DOCUMENT RESUME

ED 121 002 95 EC 082 489

TITLE Proceedings of the Conference on Research Needs Related to Education of the Severely Handicapped; January 31-February 2, 1975.

INSTITUTION Bureau of Education for the Handicapped (DHEW/OE), Washington, D.C. Research Projects Branch.

PUB DATE Feb 75

CONTRACT OEC-0-74-7366

NOTE 108p.; For related information, see EC 082 488-491 and EC 082 493

EDRS PRICE MF-$0.83 HC-$6.01 Plus Postage

DESCRIPTORS *Administration; Communications; Conference Reports; Data Collection; *Educational Objectives; Exceptional Child Research; Information Dissemination; Organizational Communication; *Research Needs; *Services; *Severely Handicapped

ABSTRACT

Presented are proceedings from a 1975 Bureau of Education for the Handicapped sponsored conference on research needs related to the education of the severely handicapped. It is explained that participants (whose names are listed in an appendix) focused upon the identification of research needs in four major areas: goals (remarks by M. Gold), service (remarks by P. Roos), communications (a paper reviewing such problems as data collection and communication between agencies by H. Leland), and management/administration (remarks by J. Budde). Reported are priority research needs cited by conference participants in the areas of prevention; early identification; assessment models of alternative service delivery systems); information exchange systems; evaluation; and a model for research, service design, and delivery. (CL)

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PROCEEDINGS OF THE CONFERENCE ON RESEARCH NEEDS RELATED TO EDUCATION OF THE SEVERELY HANDICAPPED

January 31-February 2, 1975

Bureau of Education
for the Handicapped
U.S. Office of Education

EC 082 489

The work upon which this publication is based was performed by Educational Testing Service pursuant to Contract OEC-0-74-7366 with the Office of Education, Department of Health, Education, and Welfare. However, the opinions expressed herein do not necessarily reflect the position or policy of the U. S. Office of Education and no official endorsement by the U. S. Office of Education should be inferred.

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FOREWORD

by

Edwin Martin
Chief
Bureau of Education
for the Handicapped

FOREWORD

The U.S. Office of Education is committed to assuring equal educational opportunities for all handicapped children. Efforts of the Office of Education in meeting this commitment are coordinated through the Bureau of Education for the Handicapped. Education of handicapped children has been adopted by the U.S. Office of Education as one of its major priorities. Among the objectives designed to implement this priority are: 1) to assure that every handicapped child is receiving an appropriately designed education; 2) to assure that every handicapped child who leaves school has had career educational training that is relevant to the job market, meaningful to his career aspirations, and realistic to his fullest potential; 3) to assure that all handicapped children served in the schools have a trained teacher or other resource person competent in the skills required to aid a child in reaching his full potential; 4) to secure the enrollment of preschool-aged handicapped children in federal, state, and local educational and day-care programs; and 5) to encourage additional educational programming for severely handicapped children to enable them to become as independent as possible, thereby reducing their requirements for institutional care and providing opportunities for self-development.

Research and development activities of the Bureau are directed toward providing information and developing products which can be directly related to the accomplishment of these objectives. Current planning activities, of which these conferences are a significant part, will permit us to specify better the barriers to meeting these objectives. Further, we will be able to define, and hopefully prioritize, key issues where research and development activities can significantly contribute to the overall mission of the Bureau.

PREFACE

by

Max Mueller
Chief, Research Projects Branch
Bureau of Education
for the Handicapped

PREFACE

The Research Projects Branch of the Bureau of Education for the Handicapped (BEH) is implementing a comprehensive planning effort designed to determine how research activities can best contribute to the accomplishment of Bureau objectives. The broad purposes of this planning effort are to identify significant barriers to accomplishment of these objectives, to delineate key substantive issues related to these objectives, to identify promising strategies for removing these barriers, and to address these issues through research and related activities. Initial goals are to develop long-range research plans related to Bureau objectives and to identify specific research tasks which merit immediate attention in terms of support for research and related purposes.

Our primary concern in initiating this planning effort is that the resulting plan, and especially the identification of specific tasks to be accomplished in the immediate future, truly reflect the best current thinking of the broadest possible sampling of the field of special education and related disciplines. We fully realize that our efforts must result in a program which is responsive both to the constraints imposed by our responsibilities as managers of public funds and to the needs of handicapped children as perceived by the consumers of research.

Procedures for award of grants and contracts increasingly demand that decisions regarding support for research and related purposes be made by federal program managers. If we are to implement this emerging responsibility effectively, it is critical that we increase our communication with our constituency. We can only maintain the credibility of the research program by systematically seeking input from the professional community.

The need for more definitive planning is reinforced by the severe limitations of available funds for research and related purposes. The number of problems associated with education of the handicapped unquestionably exceeds by several orders of magnitude the number that could be attacked feasibly under present funding levels. Thus, it is imperative that we not only identify issues which are relevant but also identify those issues and problems which are most critical at this point in time.

It is especially important now that we involve the field fully in the process of developing research plans and priorities. We are hopeful that the strategies outlined will assure an optimal level of credibility, relevance, responsiveness, and effectiveness in the research program. The initial objectives to be accomplished are:

1. To develop a systematic organizational schema for addressing each of the Bureau objectives
2. To identify significant content (issues, problems, needs, and so on) associated with each objective
3. To prioritize content both within and across objectives
4. To identify research strategies related to those areas where research approaches are appropriate

Research Planning Strategies

Strategies have been developed on the basis of several assumptions which, like the resulting plans, are subject to modification based on input from the field. Our basic assumptions are:

1. That practitioners are a primary source for identifying critical needs related to improvement of educational opportunities for the handicapped

2. That research expertise is essential to defining problems to be solved through research; and deciding what research or research-related strategies may appropriately be brought to bear on the solution of problems of education for the handicapped
3. That, through the interaction of practitioners and researchers, it is possible to optimize the ultimate impact of research support
4. That we will be effective in our efforts to communicate to our constituency: (a) the overall planning schema, (b) the results of each of the procedures for obtaining target group input, and (c) the overall support pattern emanating form the planning schema

Given the foregoing rationale, objectives, and assumptions, a number of strategies will be employed to establish professional relevance and credibility. At least six forms of input appear to have promise for assuring adequate communication with relevant constituencies:

1. Research Needs Task Forces
2. Position Papers
3. Needs Assessments
4. Research Integration Projects
5. Expert Reviews
6. Research Needs Conferences

Research needs task forces: Throughout the planning process, task force groups will be constituted to assist Bureau staff in accomplishing the research planning task. The composition of any given task force would depend on the specific effort being addressed, but overall, a broad range of people would be involved: federal and nonfederal personnel, researchers and consumers of research findings, special educators and personnel from multiple disciplines, and so on.

Position papers: The Research Projects Branch solicits suggestions from the field in several ways. We welcome position papers from individuals and/or organizations relating to any of the Bureau's objectives. This strategy should provide considerable input in terms of the identification of significant needs, content, and appropriate research strategies. As the research planning effort proceeds, we anticipate that certain issues may surface which will call for specifically invited position papers focusing on such special issues. Though it is doubtful that every idea submitted can be directly incorporated in the plans or individual requests for proposals, all position papers, whether specifically invited or not, will be carefully considered as these plans develop.

Needs assessments: The Research Projects Branch will identify major issues through comprehensive, national cross-sectional surveys of those involved in the education of handicapped children. Such surveys will identify content areas, and analyses of responses will also contribute to establishing priorities.

Research integration projects: In some areas of education of the handicapped, the most immediate need related to research planning is to synthesize and critically review existing information. A very large body of research on education of the handicapped has been created over the last quarter century. This body of research has not been evaluated comprehensively with respect to technical quality, utility, and potential for codification and wider diffusion. Integration and evaluation of this literature and experience are required to aid in the planning and definition of research programs concerned with improvement of educational opportunities for the handicapped and to provide a basis for potential use by local, state, and federal education agencies.

Tightly objective accounts of the present state of knowledge should be highly valuable to researchers developing plans for future thrusts and to BEH/OE, which could then develop specific program announcements or requests for proposals for work designed to fill identified gaps or to answer specific, critical questions.

Expert reviews: The primary purpose of expert review will be to provide consensual validation of content areas and priorities. Throughout the research-planning process, therefore, resulting documentation will be subjected to extensive expert reviews. Such reviews will be tailored to a great extent to the nature of any given document. However, several general considerations are immediately apparent. Whatever the content of a given document, both individual and institutional expertise will be employed to assist our staff in refining and evaluating the documentation. Certain organizations (such as the Council for Exceptional Children or the National Association of State Directors of Special Education) will be invited to participate. Some documents may require review by experts from related disciplines, by consumers, and by others.

Research needs conferences: Interaction between research and consumer constituencies will be encouraged by support of topical national forums for establishing major issues. Conferences such as this one should contribute to all of the planning tasks. Such activities are particularly important in identifying those problems in the education of the handicapped which can be addressed most effectively through research and related activities. Particular reasons for conferences of this type are: (1) to examine what has been investigated and what needs investigation in each area, (2) to describe better the role of BEH in organizing its resources for more effective research and demonstration efforts, and (3) to investigate ways of disseminating and interpreting research information so that it can be applied by practitioners.

How BEH Views Research and the Handicapped

The research program of the Bureau of Education for the Handicapped has as its mission the improvement of educational programs for handicapped children through the stimulation and support of applied research and related activities. Support is directed at providing the information and resources necessary to increase the availability of appropriate educational opportunities for every handicapped child.

In order to stimulate more effective programming for handicapped children, the Bureau is structuring its research and development program to link research and research-related activities more directly to the support of special education services. Activities supported under the research program must be applied in nature and must show promise of producing valid and relevant information. Whether an activity is applied is determined on the basis of the extent to which such activity:

1. Is a direct effort to solve some critical education problem; and
2. Is planned so that the final product of such activity can be reasonably expected to have a direct influence on the performance of handicapped children or on personnel responsible for the education of the handicapped.

A severely handicapped person is one who, because of the intensity of his physical, mental, or emotional problems, or a combination of such problems, needs educational, social, psychological, and medical services beyond those which have been offered by traditional regular and special educational programs to maximize his full potential for useful and meaningful participation in society and for self-fulfillment. Such persons include those classified as seriously emotionally disturbed (schizophrenic and autistic), profoundly and severely mentally retarded, and those with two or more serious handicapping

conditions such as the mentally retarded-deaf and the mentally retarded-blind. Such persons may possess severe language and/or perceptual-cognitive deprivations or an extremely fragile physiological condition and evidence a number of abnormal behaviors including self-mutilation, durable and intense temper tantrums, a failure to attend even the most pronounced social stimuli, and absence of even the most rudimentary forms of verbal control.

The BEH has been spending about $10 million a year on support of research and related activities, and we hope to be able to at least maintain, if not increase, this support over the coming years. The principle purpose of this conference is to obtain input from a broad range of special educators and related specialists to assist the Bureau's program planning. This fits into our larger objective of improving planning to make the most effective and efficient use of the limited federal research investment. We hope that the information generated by this conference may have a very broad impact on research programming related to the severely handicapped; we guarantee that your deliberations will influence the way the Bureau allocates its research resources.

REPORT OF THE
STEERING COMMITTEE

REPORT OF THE STEERING COMMITTEE

In September of 1974, when the Steering Committee of the Conference on Research Needs Related to Education of the Severely Handicapped first met in Washington at the invitation of the Bureau for the Education for the Handicapped, many members were skeptical about the potential benefits of such an activity. According to the BEH and Educational Testing Service personnel, one hundred of the "finest minds" in the area of severely handicapped were to be invited to attend a two-day conference at which they would work around the clock to develop a list of research priorities which could be used to guide the Bureau's efforts on behalf of the education of the severely handicapped for the next five years. Participants were to include a mixture of researchers and practitioners. The committee was to generate a list of participants, develop a conference format to insure productivity, and generally lead participants through the planned format.

However, skepticism about the conference appears to have been unjustified. Represented in the proceedings of this conference are the sum product of more than 4,500 man-hours of concentrated effort by the participants. That such efforts were expended on this project may be seen as a field response to what the various participants perceived as a very positive and appropriate movement toward the development of more relevant research patterns on the part of the Bureau.

Particularly heartening to the participants was the fact that the severely handicapped were picked as one of the important target populations for which relevant research must be planned and integrated into future BEH activities. In addition, the participants were delighted with the responses of the BEH staff to the highly practical applied research projects which constituted the many recommendations generated by the conference.

Several issues arose during the conference which deserve particular attention. Perhaps the most pressing of these was one of clear definition. Marc Gold and Philip Roos, in focus presentations, both stressed that there is no functional floor to the category of severely handicapped. Although participants were able to identify a variety of individuals or groups who could be considered severely handicapped, a clear and succinct definition eluded the conference. A clear definition and some standard terminology would be most valuable; as Henry Leland suggested, "communication should get less esoteric."

Another important issue concerns communication and dissemination of information. Participants agreed that if two-way communication between practitioners and researchers could be established, research would become more relevant and practice more effective. Many participants felt that much current research is conducted in isolation from the actual classroom student needs and that effective systems of communication and dissemination will help pull together these dual efforts. All conference participants, including researchers, BEH consultants, and practitioners, shared this desire for better research efforts. Generating such systems could become a major goal of the conference. We hope the development of communication-dissemination systems will have an impact on the creation of new strategies and methodologies for dealing with the severely handicapped population. That is, many of the tasks which need attention will require new measurement/evaluation paradigms in order for practitioners to monitor and determine relevant instructional effects.

Members of the Steering Committee feel it is important to follow up the results of the conference in order to determine what impact the priorities that were established finally have on research over the next few years. It has been suggested that the proceedings of this conference be widely disseminated. Two groups for whom information from the conference is of particular importance are state directors of special education and members of the American Association

for the Education of the Severely/Profoundly Handicapped. Perhaps we should also disseminate with these proceedings a list of criterion-referenced variables which the Bureau may identify as a result of scrutinizing the listed priorities. Progress toward these criteria could be tied into the evaluation designs of RFPs which result from conference suggestions. As future conferences are held, BEH could review progress toward criteria and suggest modifications based on new knowledge. At least this would provide a working base.

Finally, the committee would like to thank the Bureau for the opportunity to participate in this landmark conference. We should like to thank the staff of Educational Testing Service for their excellent synthesis of our work, their gracious hospitality, and untold aids of every kind. Foremost, however, were the outstanding efforts on the part of the participants themselves: The Steering Committee unanimously agreed that they were well selected.

INTRODUCTION

Primary among the concerns of the Research Projects Branch of the Bureau of Education for the Handicapped (BEH) is the question of priorities: Of all the research needs that might be identified about the education of the handicapped, which are the most crucial to pursue over the next five years? As part of its response to that question, the Bureau has involved special education practitioners, researchers, and others in the field in planning research priorities for the 1970s.

The Bureau carried out this dialogue with its colleagues in the field by holding four two-day workshop conferences, each of which involved from 66 to 91 persons representing various levels of concern for, and knowledge of, the handicapped, and each planned by a steering committee of 10 to 18 members. Each conference focused on finding the priorities and research needs of one aspect of education for the handicapped. The four topics considered were: 1) career education for the handicapped; 2) education of the severely handicapped; 3) early childhood education of the handicapped; and 4) development of personnel to serve the handicapped.

Background of the Conference

The success of the Conference on Education of the Severely Handicapped depended as much on careful planning as it did on active and creative participation. A crucial first step was the selection of the Steering Committee. On August 7, 1974, staff members of BEH and Educational Testing Service (ETS) met in Washington, D. C. and selected 18 persons--BEH staff members who were most knowledgeable about the field,

the most concerned and knowledgeable individuals from related federal agencies and regional offices, and others throughout the country most expert in and aware of research and programming in each of the areas of career education for the handicapped.

The members of the Steering Committee for the Conference on Education of the Severely Handicapped (the names of the members are listed in Appendix A) met in Washington, D. C. for a two-day conference from September 16 to 18. During those two days, the Steering Committee members laid the foundation of the conference and developed the conceptual model shown as Figure 1, page 5. From their knowledge of and experience in the field, they decided on the topics, or tasks, to be addressed by the participants and then worked out the focus session/work session structure to accommodate them. They also decided on the dates on which such a conference could be given to gain maximum attendance. They drew on their knowledge of the people in their field to identify possible conference leaders who, in turn, would be helpful in suggesting possible participants. The committee members were helped in the task of nominating participants by chief state school officers, state directors of special education, and officers of professional organizations and associations throughout the nation who sent in suggestions by mail.

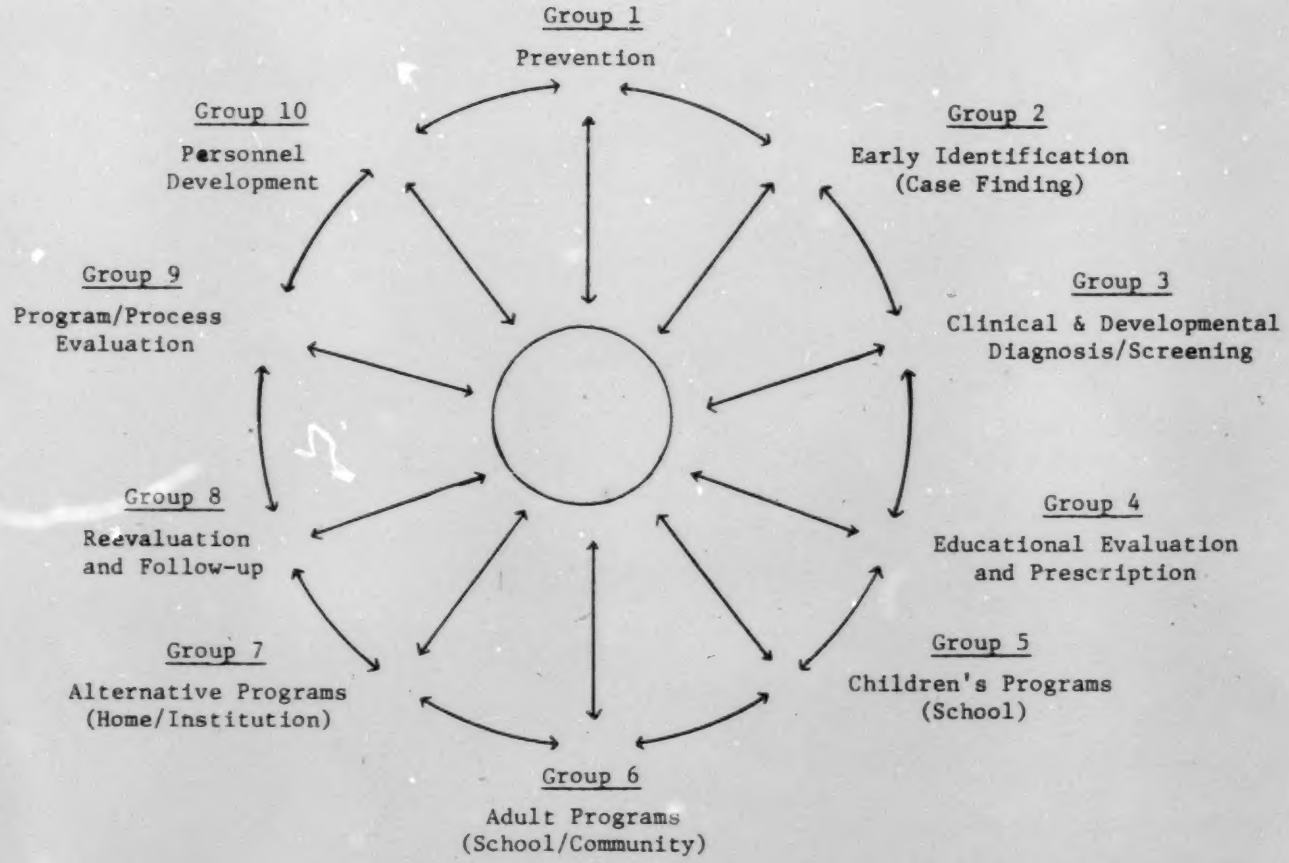
In November, the members of the Steering Committee officially nominated those whom they felt would be the best participants for the conference. They also reviewed and approved their earlier suggestions about the content, dates, and structure of the conference. The names of those nominated by the Steering Committee were then reviewed and approved by the BEH Project Officer and those people, together with others nominated by the Bureau, were issued invitations to the conference.

The Conference

The Conference on Research Needs Related to Education of the Severely Handicapped

Figure 1

Conceptual Model
for the Conference on
Identification of Research Needs Related to
Education of the Severely Handicapped



was held at the Henry Chauncey Conference Center at ETS in Princeton, New Jersey from January 31 to February 2, 1975. The two-day session was a workshop conference of 91 participants that focused upon the identification of research needs in four major areas: goals, service, communications, and management/administration. Ten groups participated, each of which considered the four areas from its own orientation. Participants represented expertise in the 10 areas that had been determined by the Steering Committee in the development of the conceptual model: prevention, early identification, clinical and developmental diagnosis/screening, educational evaluation and prescription, children's programs (school), adult programs (school/community), alternative programs (home/institution), reevaluation and follow-up, program/process evaluation, and personnel development.

The conference was structured in a modular fashion with participants addressing each area, or task, in both large- and small-group work sessions. For each task, all participants met first for a focus session during which a speaker provided a stimulus for the work sessions that followed by exploring various aspects of the subject. In the focus session on goal-related research needs, for example, Marc Gold outlined some of the problems and surprises that are part of working with deaf, blind, and severely retarded individuals. In the session on communications-related research needs, Henry Leland discussed the problems of gathering, storing, and retrieving information in data banks and of communication within and between institutions and between individual researchers.

After each focus session, the 10 teams went to their own meeting rooms to identify and explore researchable ideas in each task area. This was accomplished in two steps: first, by getting down on paper all the research ideas each team could think of within a reasonable time limit and second, making a selection of those ideas, refining them, writing a rationale, and suggesting possible research approaches and the potential uses of such research for each.

The conference participants began with their first focus session late Friday afternoon and concluded their initial brainstorming sessions late Friday night.

Beginning at nine o'clock on Saturday morning, they continued alternating focus sessions with team sessions until they had covered all four tasks late Saturday night.

On Sunday, the final day of the conference, the members of each team reviewed all the research ideas they had generated since Friday night to select the four most important (one from each task area) and from those, the one top-priority research need.

A summary of the research needs recommended for study by the conference participants--the top-priority needs announced on Sunday and the runners-up from which they were derived--are listed and discussed in "Recommendations" beginning on page 69.

TASK 1:

Identification of Goal-Related
Research Needs in the Education
of the Severely Handicapped

Remarks by

Marc W. Gold

Children's Research Center

University of Illinois

"You can't make a silk purse out of a sow's ear," they say. The people we're concerned with here have always been considered sows' ears. Some say you can improve the quality of the leather, but I wonder. I wonder if some of us are sitting here and thinking that we're at a conference where, for a variety of emotions, like benevolence, guilt, or humanitarian feelings, that somehow we're coming together to see if we can't improve the quality of the leather of a bunch of sows' ears.

Or is it possible that we have a whole bunch of silk purses on our hands? I don't think there are any sows' ears out there at all. If I'm going to meet the responsibility I've been given so that you go out into your sessions this evening to write a list of goals, it seems very important to present to you three or four notions for your consideration.

Expectancies

The first one relates to expectancies. We have an expectancy cycle in our business that's deathly. An expectancy cycle works not only with the severely handicapped but with all handicapped individuals. Over the years, we have come to arrive at decisions of what people could do or what they couldn't do and as self-fulfilling prophecies, they've always gone out and proven us right. In the last few years, we have also had laws and court decisions which mandate that we have to go do something. Well, who's likely to go do something, even under a court order, if they don't think anything can be done? What if there was a court order that said we have 90 days to get every severely retarded, deaf-blind individual in your state out earning

the minimum wage or more? I suspect that some of you would react and say court order or not, litigation or not, morality or not, how can you do that? How's it possible?

The Ugly Ball of Normalcy

There are people here who have been very much involved over the last 10 or 15 or 20 years in attempting to help us decide what it takes to get into what I call the "ugly ball of normalcy". The reason I call it ugly is because once you get there, there isn't much reason to do any more. If you acquire all 99 behaviors, are you okay? Are you and I people who behave normally? Are we people who fit the 399 pieces of the Camelot Checklist or the 99 pieces of the A.B.S.? Is it likely that deaf-blind and severely retarded blind individuals will become our peers? Might there be an alternative notion of what normal is?

None of us is normal in the same way. Each of us has competencies and deviances. What I call the Competence-Deviance Hypothesis says: The more competence an individual has, the more deviance will be tolerated in him by others. (Some of you do an excellent job of testing that hypothesis.) Well, we don't take that into consideration with the severely handicapped. We tend to bring severely handicapped people up to zero by trying to get rid of all the things about them that bring negative attention. What about balance? What about giving them the kinds of skills, competencies and life styles that distinguish them positively from other people in society? Why don't we give them something to put into an account, something that they can draw against so that if there are things about them, like physical appearance, that make people uncomfortable, there will be something else about them that makes people want them there? Some of you don't look so good, but there are a lot of people who really like having you with them because there is something else about you that's important, that they need.

I'd like to describe to you some of the competencies of the severely handicapped. I hope when I finish you'll see that the term "severely handicapped," as I use it,

has no boundaries. In the discussions last night, I got the impression that many of us still think of the severely handicapped as including this group but not that group. At this conference, there should be no lower boundary to the severely handicapped.

When you see an individual doing a work task and there are things about that individual that make you wonder how productive he is, or how lazy he is, or whether or not he should be working, you might consider this: The task that he's doing, if it's putting pieces of cardboard into pieces of cardboard, for example, is one of little status in our society. But the people who trained this individual did a fantastic job. The particular motor movements he makes in order to get the pieces together just fantastically exceed what anybody thought a person with such severe motor control problems could do. Someone made a decision that he would be able to and then wouldn't stop until he did.

I knew some of my friends from Western Carolina Center were going to be here so I thought I'd tell you about a young man named Klaus. Klaus is profoundly retarded deaf-blind. He went through a training session where he acquired some of the skills for putting a fifteen-piece assembly task together. He represents an increasing number of individuals we have worked with in developing a technology of instruction so that people with characteristics like his can accomplish complex tasks.

Richard is blind, he tests out with an IQ of 33, and was trained to work on a locking gas cap. He is among the group of individuals we worked with who are severely retarded-blind, deaf-blind, and profoundly retarded-blind who, in working on the bicycle brakes, learned to put them together in an average of 23 trials to criterion, which incidentally, matches the trials to criterion of the severely retarded sighted people we have worked with. This supports the assumption that the

difference between people is not what they can learn but the power needed in the training process required for them to learn. Let me say that differently. The difference between one person and another is not what each is capable of learning, but the amount of power the trainer needs in order for each to learn. When we began working with blind and deaf-blind individuals, we modified our training procedures. We took a group of 12 severely retarded blind individuals whose mean age was 32, mean IQ, 33, mean length of institutionalization, 21 years, and whose number of mean trials to criterion was 23, which matched our data with sighted individuals. That upheld the hypothesis very nicely. Their criterion behavior was not any different from anyone else's, but our training behavior had to be.

Who's Retarded?

During the fuel shortage last March, the company that manufactures locking gas caps went to all the sheltered workshops in our area (which is a switch) and begged them to build these things. One of the workshops worked two full days with two high-level sighted educable individuals to teach them how to put these units together (the units have very small springs; it's a very complex task). At the end of two days, they gave up. They could not teach their high-level sighted kids to do it. Two people at Dixon State School who have been training on the bicycle brake assemblies took the tray that we use for teaching the bicycle brake and the data sheets, scratched out the names of the bicycle brake parts and replaced them with the names of the gas cap parts. Then two severely retarded-blind individuals who had learned the bike brakes went over to the sheltered workshop and in less than two hours' time, were successfully producing locking gas caps. There may be a message there. You know: Who's retarded? Who's severely handicapped?

Mary Merwin did a study for her master's thesis with 45 retarded individuals at Lincoln State School. Their IQs ranged from 23 to 92. The mean IQ was 55. They worked with a printed circuit (P.C.) board with 12 components on it and 280 holes in it. Out of 45 people, 39 successfully completed the task. That meant that they had to put this unit together--remember that there were 280 holes there and you've got to find the right 24. They had to put this together five times in a row without any errors and without any assistance. In other words, they had to put these resistors in correctly 60 consecutive times. When they reached this criterion, they had to then learn to assemble a second board with 12 different pieces in different places. If a person put 55 components in correctly and then made a mistake, he started again from 0. The average time that it took the 39 individuals to go through pretraining to learn to do this board and the second board was 170 minutes. The correlation between IQ and how long it took was .03. In other words, individuals--some of whom had been in Lincoln for years--in an average of less than three hours' time, were producing something that I know society needs to be produced. And when it was over, they had to go back to being severely retarded.

On another P.C. board that Dr. Merwin used for her Ph.D. thesis, we trained 60 individuals in a large sheltered-care home in the Chicago area. The results were virtually the same as in her first study.

We're now working with a circuit board with moderately and severely retarded individuals in a sheltered workshop in Champaign, Illinois. There are 59 components on this board. The training is on assembly of 35 of the components. Two severely retarded individuals have been trained. One reached a criterion of 5 consecutive correct boards--that means 5 times 35 consecutive perfect insertions--with 119 minutes of training. The second individual reached criterion in 70 minutes.

Billy's Story

About nine months ago, at Dixon State School where we have done our pilot work with the blind and deaf-blind, I had occasion to work with a young man named Billy Widmar, who, using conventional labels, can be described as follows: profoundly retarded with a reported IQ score of 6 (whatever that means); totally blind; totally or functionally deaf (no reactions to any sound whatsoever); severely self-destructive; and pretty damaging to anyone who gets in his way (people have had surgery from his bites). I think this fairly describes some of the individuals we're supposed to be interested in at this conference.

Billy was 17 years old when I sat down with him with the bike brakes. It was very interesting. When I put his hand down on the first part--on the axle--and touched the inside of his palm with the axle, his hand didn't close. Now he's capable of closing his hand, he's capable of grabbing. But when something was put there, he didn't do what the normal infant would do, which is to spontaneously close. When I reached over and closed his hands around the part and then reached back to his wrist and lifted his hand up, the part didn't come with his hand. There was no maintaining of the closure. So I put my hand back over his, put the part inside, and then moved his hand over. That's where we started.

By the time four or five minutes of training had passed (and some of you have seen the videotape on this), I would reach over and direct his hand down to the board, then, independently, his hand would go down and touch a part--positioned so that the part was in the palm--close, his hand would lift up and would move over and down. After 17 years of almost total sensory deprivation, he walks in and somebody says "Build a bicycle brake." And he says "I don't have a pincer grasp." And five minutes later, he has acquired a series of six consecutive behaviors that add up to reach, position, grasp, lift, move, and place. After 17 or 18 minutes of training, he could spontaneously reach, position, grasp, lift, move, connect, and adjust. In

other words, he would touch this part to other parts and would understand that it wasn't right and would move it up again and move it over again. And then (and this is really interesting) at some point--and it happened that the points were right--he let go and moved his hand down.

What does that say? What does it tell us in terms of going out and writing goals tonight? What if we had worked with him from birth? He was a profoundly retarded, deaf-blind person. I am sure the severely self-destructive behavior wasn't present at birth. You just heard a little bit of what happened after 20 minutes of training. By the way, I had never worked with people as difficult as Billy. I have since then, but up to that time I had insufficient power for someone like Billy. I had lots of power for working with moderately and severely retarded sighted people. Practically all of them learned the tasks we use--the circuit boards, the bicycle brakes--but someone like Billy, he just sat there. If he could have spoken, he'd have said "Gosh, you're a sloppy trainer." Because I didn't know how to feed back to him. So here's a guy getting lousy feedback, after 17 years of nothingness, having severe demands placed on him, and as long as he's at it, he goes and learns a sequence of eight or ten sophisticated behaviors. What if we had been training Billy from birth? What if our society said "Here are all the resources you need to do it. Go do it." Now can you sit there and tell me that Billy wouldn't have language? Can you tell me that he wouldn't be able to make a living? Can you tell me that he couldn't live next door?

Now comes an interesting thing: You can't. Now comes a second interesting thing: Can I tell you that he could? No. But now we're halfway. A lot of you have as much data, if not more, than I do. We have enough data now to say we honestly don't know. We have plenty of data on these people we think are the most difficult to reach, data that says if we don't try, we'll never know, and we now know enough to know that we don't know.

So when you're planning your goals this evening, when you're saying "The next five years--what do we want to know? What do we want to find out about?," don't think you want to find out if you can toilet train them or that you want to get them to the point where they can sit up if they couldn't before; or, if you're talking about some people who have some mobility already, that they can get to your classroom and sit down. Recognize that we might be talking about a group of people who can more or less make it into the ugly ball of normalcy just like you and me; that it may be that they're capable of acquiring skills that are so important and needed by society that the things we'll never be able to change just aren't so important anymore.

The definition that I have developed from our experiences on training states: Mental retardation refers to a level of functioning which requires from society significantly above-average training procedures and superior assets in adaptive behavior, manifested throughout life. The mentally retarded person is characterized by the level of power needed in the training process required for him to learn and not by limitations on what he can learn. The height of a retarded person's level of functioning is determined by the availability of training technology and the amount of resources society is willing to allocate, and not by significant limitations and biological potential.

Am I suggesting that a Billy Widmar could be a nuclear physicist? If we had just got him early and spent enough? I really doubt it. Can I tell you an absolute "no?" Believe it or not, I don't think I can. I seriously think Billy wouldn't live long enough, even if we tried. Because powerful training procedures are slow. Slow at best. But if this conference had taken place five years before Billy was born, he might now be perceived as a mildly retarded person, or a bit strange, but earning a living like the rest of us. I just think he might. And I think you ought to kick that around.

I would like you to consider the possibility that mental retardation is most meaningfully conceptualized as a phenomenon existing within the society, not in the individual but in the society, which can only be observed through the depressed performance of some of the individuals in that society, a society that has a profound inability to train. We've never had to train. We do too good a job of screening to ever have to train. But those of us who are here teach the field to screen in only one direction. And that's to screen people in. And the only way to screen people in is to make an assumption and believe it--that anybody who comes to us is capable of learning anything we want him to know. We have not the technology, the philosophy, nor have we expended the resources to make a statement that any person is incompetent. That has never been tested with or by any of us, severely retarded or not.

So when we write our goals tonight, let's consider that those goals have to deal with people who have never in their lives had the slightest opportunity to demonstrate competence, genuine competence. And that all our decisions about them are based on a preconceived notion that they don't have any.

We have a lot of data that says whenever you sit down and carefully plan your training strategy, carefully assess the kinds of feedback that you're going to provide, and generally expect that person in front of you to acquire the task, he always does. That's not naive; I really believe that.

The Issue of Labeling

Some of us get involved with this issue of labeling. I wonder, in our planning tonight, when we think about the notion of diagnosis and testing and labeling, if we shouldn't recognize the difference between those activities that are designed to meet administrative convenience and those activities that result in genuine information to help people. I don't think I've ever seen a test that made me feel better about someone than I did before. So how come we test? We need labels. How can we give funds to treat someone unless he fits the label that the money is attached to? Fine.

But should we fool ourselves into thinking these labels tell us something about the individual? Those labels have duped society into causing those people to act in a way that reflects our labels. Keep that in mind.

Two Populations, Two Approaches

Another thing to keep in mind is that we have two very separate groups, the old ones and the new ones. There are a whole bunch of retarded and physically handicapped and other kinds of handicapped people in this world right now. A large majority of those individuals have already been exposed to our incompetence. They have a right to some service. Goals should reflect a concern for those people who have already been ripped off by our society. But there should be separate goals also for those individuals who are not yet born. They will be ready to start learning and developing, without a hopelessly bad start, but will still need a great deal of assistance. I see those as two separate problems.

Why is it when we define the handicapped, we talk about their maladaptive behavior? About their inability to adapt? And we always infer that those of us who are not handicapped are the ones who can adapt. We have designed every career and all of our training and all of our philosophies and goals in such a way as to require them to do the adapting. Part of the currently accepted definition of retardation says they don't adapt. So what do we do? We take hours and hours, for example, to try to teach them to fill out a job application. Do we walk into an employer's office and say "Don't you realize that the only people who can get a job here which doesn't require anyone to read or write are people who read and write?" Why is it that all of our efforts are to get people we define as unadaptive to adapt. And ironically they've been showing it all the time. When a kid sits and rocks in a ward, are you calling that maladaptive behavior? What else have you given him to do?

Let's consider in our goals the task that most of us have always been afraid of and always said was not our job. What about goals relating to changing some of the

screwed-up values of the society we live in? A society which sees a normal man and a severely handicapped man working side by side and doing the same thing as a reflection on the normal man. If we don't do something about that, we can do a lot of training with the severely handicapped and it's not going to do much good when we're finished. Why don't we see if we can help all those people to become so competent that we are afraid to make decisions for them?

Let me close with a poem. Some of you know that I like to do that sometimes.

If you could only know me for who I am
Instead of for who I am not,
There would be so much more to see
'cause there's so much more that I've got.

So long as you see me as mentally retarded,
Which supposedly means something, I guess,
There is nothing that you or I could ever do
To make me a human success.

Someday you'll know that tests aren't built
To let me stand next to you.
By the way you test me, all they can do
Is make me look bad through and through.

And someday soon I'll get my chance,
When some of you finally adapt.
You'll be delighted to know that though I'm MR,
I'm not at all handicapped.

TASK 2:

Identification of Service-Related Research Needs in the Education of the Severely Handicapped

Remarks by

Philip Roos

National Association for Retarded Citizens

Just a little over 50 years ago, one of the foremost figures in the area of aviation, Orville Wright, evaluated the possibility of crossing the Atlantic by air and concluded very definitely that it would be scientifically impossible to do so. He had quite a treatise on the subject which I won't bother reading to you but in essence, he said "No way, babies, can anybody ever fly across that Atlantic and survive."

We are all prisoners of our past. We develop self-limiting and self-fulfilling prophecies. At the same time, we are living in an age of telescoping time. The future is impacting upon us. As you know, Alvin Toffler wrote an exciting book in which he referred to this phenomenon as "future shock." He described the future as transient, filled with novelty, and characterized by increasing diversity.

We are told that 90 percent of the scientists who have ever walked the earth are walking today. Many of us, ladies and gentlemen, would have gone down in history as luminaries if we could have lived a few centuries earlier. Today the competition is so stiff that we're all schnooks among many schnooks. All of us are suffering from a technological explosion and an information overload. There is more written and printed and discussed than any one human being can ever hope to absorb even within his own field. The practitioner, the person who is out in the field trying to actually implement today's technology, is buffeted by an avalance of trivia, irrelevancies, and esoterica. As a result, he is frustrated, he is anxious, and frequently he responds by developing escape and/or avoidance responses. At the same time, the researcher is competing for attention. Researchers who are beginning to be challenged by problems of marketing--of getting their wares exposed to the public, of making a significant impact on the consumer--are faced with a multiplicity of target audiences and they, too, are frustrated. To make matters worse, they--or we--are

continually reminded that we are failing to implement research findings, that there is an increasing lag between discovery and its implementation. In the field of mental retardation, for example, we are told that today we could prevent 50 percent of the cases of mental retardation if only we could implement what we already know. It appears at times as if we are living in two different worlds--the world of research on the one hand and the world of practice on the other.

In the field of handicapping conditions, it appears to me that today we are operating on the basis of four or five basic principles, principles which in point of fact are shaping our service delivery system; principles which are being incorporated in national standards, in court decisions, in litigations; principles which, mind you, are accepted primarily on the basis of faith rather than on the basis of science. Let me review these principles very briefly, because I know that most of you are extremely familiar with them:

Some Basic Principles

The first is a tendency to adopt the so-called developmental model of handicapping conditions, a model which stresses the potency of the environment and the malleability of the organism. In expanding the developmental model, we at the National Association for Retarded Citizens have suggested that service programs, in order to conform with a developmental model, should increase the complexity of the behavior of the client; should increase the client's capacity to cope with his/her environment (and by coping with the environment we include the self, the social environment, and the physical environment). Finally, programs should enhance the human qualities of the client, as these are culturally defined.

The second basic principle which is creating a major impact today is what is called the normalization principle. Again, you are all very familiar, I'm sure, with the concept of normalization and the modification of it by Wolfensberger.

Normalization is closely affiliated with certain legal principles which are impacting on services today--namely, the principle of the least drastic alternative and the least respective environment. These principles are related to the 14th Amendment and, as you know, have been involved in class action suits dealing with right to education and right to treatment. Normalization is an extremely appealing principle. It is easy to understand--even practitioners, mind you, understand normalization--and it is relatively easy (or, at least, so it would appear) to evaluate the degree to which programs are indeed normalized. It seems that today deviations from normalization are being condoned when these deviations are more effective in achieving specific objectives. What I'm saying is that if non-normalizing practices are more effective in reaching stipulated individual goals, then these deviations are considered to be valid. However, if normalizing practices are equally effective, then they should be used.

The third principle is the principle of individualization, the recognition of the uniqueness of each handicapped person. Hence, we see increasing emphasis on the individual program plan, on prescriptive programming, on the recognition that we must avoid regimentation.

The fourth principle is what I call the principle of self-actualization, borrowing a term from Mazlow. It is a principle which states essentially that each handicapped person should be given the maximum opportunity to determine his own course, to shape his own destiny. Now this principle leads to the conclusion that, as we program services for individuals, we must maximize opportunities for having the client make his own choices among alternatives. Essentially, the making of choices among alternatives is what freedom is all about. Bob Perske has written eloquently about risk taking and the dignity of taking risks. Some

of us are beginning to look very seriously at modifying the environment so as to make choice possible for the severely impaired, for the multiply handicapped.

The fifth and last principle is the principle of independence. In its latest publication, the President's Committee on Mental Retardation has included a chapter by Jennifer House in which she enunciates the principle of independence as a new national goal. She cites physical functioning (including mobility, transportation, and so forth), economic functioning (the development of work skills), and social functioning as the three areas in which independence is important.

These, then, are the major principles which are shaping the delivery of services today. If you focus more specifically on the field of education--particularly special education--you find that there are some generalized trends which are impacting on both services to clients and on research.

Major trends in the field today include the following: Changes in definition which are generally aimed at avoiding stigmatizing on the one hand while broadening the ability range on the other. Hence, we no longer accept such terms as "custodial," "subtrainable," and so on. We are broadening the age range of our clients so that we now consider that education is a life-long process beginning with conception and terminating, so far as we're concerned, with death. Decentralization of specialized services is gaining momentum, as are the concepts of integration, mainstreaming, dispersal, and so on. There is a growing emphasis on a pragmatic orientation--that is, increasing focus on self-help skills, social skills and work skills, as opposed to the more traditional academic orientation. An escalation in innovative technology is characteristic of special education today, including behavior modification, the use of automation, the use of ancillary staff, discrimination learning (the House and Zeeman type of approach), and so on.

There is increasing involvement of parents in the educational process--parents as decision makers, as ancillary trainers, as home trainers, as members of the training, education, and treatment team. Finally, we are witnessing an increasing focus on quality control, effectiveness measures, and output measures. In short, we are entering into the planning-programming-budgeting system era in the field of special education.

Orchestrating Research and Service Delivery Systems

Now, I'd like to talk to you briefly about what I see as a major challenge to all of us and to BEH--that is, orchestrating research and service delivery systems. This is truly a major challenge. Indeed, this very issue of how to orchestrate research and service may well be the focus of some significant research questions and research investigations. Let me then quickly summarize some of the important issues related to this orchestration of research and services.

First is the issue of agreeing on the target population. There has been a tendency to define our target population so as to exclude the more severely handicapped. There is a tendency for us to play what I call the "change the label" game. The "trainable class" becomes the "severely retarded class", but it contains the same happy little Down's syndrome kids. Thus, there is a need, I would think, to get a very clear understanding among all of us as to exactly the type of population we are talking about.

Second, consider problems of communication. There is a tendency for us to develop our own jargons, as I'm sure you've noticed. Practitioners tend to develop one type of jargon and researchers another. We need common areas of communication and we need the opportunity for feedback systems. Frequently, we do not have these.

Next, let me touch on issues of priority and relevance. How applicable is our research to the practitioner, to the clinician, to the consumer? The whole issue of relevance, of course, is directly related to the focus of this conference because as

I understand it, this conference gives the practitioner an opportunity to have input into determining priorities (degree of relevance of various research tasks). In this connection, I think it's important for us to recognize that we operate under different types of reinforcement. The researcher and academician are primarily rewarded for developing clean research designs, low-risk research, research that has little controversy associated with it. The practitioner, on the other hand, is rewarded by success with his individual client--he is rewarded by the parent or administrator. These are very different types of "m and m's" as it were.

Also related to the issue of relevance is the issue of specifying concrete goals and objectives. In this connection we, as educators, are particularly concerned with problems of generalization and retention--of long-range consequences of our interventions. There is a tendency in research to focus on the immediate impact of intervention, so that if the individual develops, for example, self-help skills in a given situation, we consider the intervention successful without evaluating its long-range impact.

Let us move now from concrete considerations to the more philosophical and abstract. It is important for us, I think, to recognize that we operate on the basis of implicit value systems, and that it is quite likely that some of these value systems are inconsistent or may indeed be in conflict with each other. When we spoke of goals yesterday, I'm sure that many of our work groups dealt with this very issue. When we set up goals for individuals or groups, these goals are based on implicit values. An interesting research question is: Whose values do we use? The administrator's, the teacher's, the parent's, the legislator's, or the client's? Seldom the last, I fear.

Let me just suggest to you some common implicit value systems. (It is important to make these explicit, particularly when we design research and intervention programs.) There is the value of independence--the importance of making

individuals more independent. Often we operate as if this were, a priori, desirable. Sometimes I characterize our culture as a John Wayne society--standing on your own two feet, gritting the teeth, and saying "Baby, I don't need anybody." It's conceivable, mind you, that dependency may be an important value and indeed, for some individuals, the establishment of symbiotic relationships may be more valid than the goal of independence.

The developmental model is predicated on a different value system--namely, that every individual should maximize his own potential. Isn't this a familiar phrase that we use? Our society is an achievement-oriented society. Particularly those of us who are in leadership positions have been dominated by strong achievement motivations or we wouldn't be where we are--we'd be sitting on the beach in Carmel sunning ourselves or doing something equally pleasant. Yet we assume that optimizing potentials is a universal good.

We are still largely dominated by the protestant work ethic. Vocational rehabilitation programs are predicated on the work ethic. We spend infinite amounts of time preparing ourselves and others for being "productive workers." Mind you, this is also based on a value judgment--on the judgment that to be economically productive is somehow good or desirable. I'm not knocking it; I like to eat regularly, but I think it's important that we recognize that it is, after all, a value judgment, not a categorical imperative. There is indeed some suggestion that the mores and values of society may be shifting and that the value which we still place on work may be de-escalating in years to come. I hear people talking of 30-hour weeks, 20-hour weeks--you know, the whole scene.

I've already alluded to another value, which is inherent in the concept of normalization--the assumption that it is better to be like the majority of people than it is to be different from the majority of people. Yet it should be noted that our society is moving toward greater and greater acceptance of deviance, of individual variation. Although we may give lip service to the concept of self-actualization,

actually we find that many of our programs and services are designed to mold human beings to conform to some external locus of control.

Finally, we must recognize, I think, an important value system which is seldom made explicit--a hedonistic value system. I am referring to the concept that the greatest good is happiness, contentment, satisfaction. I suspect, for example, that if you conducted a research study as to the types of values held by different types of people, you would find that parents of retarded children or parents of multiply handicapped children may basically hold a hedonistic value system. To them it may be more important that their child have a happy and contented life than that he be productive, or normalized, or achieve maximally.

Some Unvalidated Assumptions

It's important for us, as we embark on this journey together, to recognize that we tend to operate on the basis of what are sometimes unvalidated assumptions, situations in which faith tends to replace science. For example, there is an assumption--which many of us would seriously question--that the more handicapped the student, the less sophisticated the teacher: If you're going to teach postgraduate courses, you need a Ph.D.. If you're going to teach profoundly retarded kids, you don't need anything. You're familiar with this kind of assumption. I recently evaluated a state institution for retarded persons and was told by the superintendent that he was having a great deal of trouble with the state personnel office in setting up positions for qualified special education teachers because the overall intelligence level of the institution's clientele was decreasing. Whereas in the past he'd had moderately and mildly retarded kids, he now had profoundly retarded kids, and the state agency was saying "Well, for that you don't need certified special-ed teachers." A rather bizarre assumption, but a very real one.

We make assumptions regarding the impact of labeling--labeling is bad, it stigmatizes the individual, it generates self-fulfilling and self-limiting prophecies,

and so on. In point of fact, there is very little research to validate that assumption. A recent article in The American Journal of Mental Deficiency reviewed the research on this assumption and concluded that there is no research validating it. We accept it on the basis of faith.

Behavior modification yields a number of other examples, not the least of which is the assumption made by some that behavior modification operates essentially on the basis of lack of awareness by the victim. Apparently, nothing could be further from the truth. Research indicates that if the victim is aware of the manipulation, if he's aware of the reinforcement contingency, the process operates much more quickly and effectively.

There is a general assumption that increasing the staff-to-client ratio improves services. Indeed, many of our standards are predicated on establishing high teacher-to-student ratios or attendant-to-resident ratios. Again, I'm sorry to say that research does not validate that assumption in many cases. Indeed, increasing the ratio of nurses to patients, for example, or of ward attendants to people living on the ward has apparently no impact at all on any dependent variable. However, all of these assumptions furnish interesting areas for research.

It's important for us to recognize that we are dealing with a multiplicity of subcultures. Our society is truly heterogeneous. There is a tendency to fail to recognize that we are dealing with varied mores and varied norms. We are dealing with a multiplicity of languages as well as subcultures and bilingual individuals and individuals who have only one language which happens not to be English. Frequently we fail to recognize this. Generally, our tendency is to shape our clients into our own images. When I was a practicing psychologist, I selected, of course, highly intelligent, highly verbal, only mildly disturbed obsessive compulsives because that's the way I visualized yours truly. I was shaping these little victims into an idealized image of myself.

Another value issue is the locus for decision making. In service programs, decision making can occur at all levels--the administrator, the researcher, the practitioner, the client, the parent, or sometimes, ideally, a combination of all of these.

And, finally, as we attempt to orchestrate these service delivery and research components, we need to be aware of the personal dynamics involved--the issues of status, turf, empires, suspiciousness, stereotyping--all of these good interpersonal dynamics which we would all like to deny, but which unfortunately impact very significantly on our work together.

A Few Suggested Strategies

To conclude, let me suggest a few strategies for facilitating our work together as researchers and practitioners:

1) The establishment and the support of effective communication mechanisms: By communication mechanisms I mean primarily opportunities for on-going dialogue, situations in which we can set up cybernetic feedback mechanisms. This includes formalized arenas for two-way communications. The type of situation that we are engaged in today is, I think, a superb prototype for the kind of situations which should exist on an on-going basis involving continual feedback between the practitioner and the researcher.

2) Research on the implementation of research findings: What kinds of techniques are effective in disseminating research findings? What kinds of techniques are less effective or ineffective or counter-productive? To what degree does research impact on human beings? What is the degree of lag time between a piece of research and its ultimate implementation on human beings?

3) The establishment of a mechanism for periodically reassessing research priorities: Today and tomorrow we are going to develop research priorities, as I understand it, which will have significant impact on BEH and, hence, on the nation. It's important, I think, that these be periodically and rather frequently reassessed, for the relevance--the value--of the findings is going to change rapidly in this

age of rapidly accelerating time. We may need to use sampling techniques, survey techniques, confrontation opportunities, which will allow us to modify our priorities and our goals as we travel through time together.

4) The adoption of systematic strategies for coping with the future: We must try to anticipate and to adapt to what lies ahead. As you know, there is a new quasi-science of futurism, individuals who specialize in developing scenarios, conducting Delphi studies, using various other technology, in an attempt to at least anticipate possible and probable futures. It behooves us as scientists or as practitioners, I think, to develop some liaison with these types of individuals so that together we can indeed cope with the future. In our own area of special education, for example, I am convinced that we need urgently to seriously consider space technology, to consider prosthetic environments for the profoundly handicapped individual, to consider the whole area of biofeedback and its potential implications--yes, even to explore the advances in parapsychology, would you believe. We can no longer afford to be self-contained specialists.

An Important Responsibility

Let me conclude now by suggesting to you that, although we may be prisoners of our past, and although we may feel like victims of the future, man can shape the course of history and, indeed, can control his own destiny. BEH should be complimented, I think, for sponsoring this conference, which is designed to help shape the future of thousands of important human beings--human beings who have too long been neglected. Ladies and gentlemen, we have an important responsibility.

TASK 3:

Identification of Communications-Related Research Needs in the Education of the Severely Handicapped

Identification of Communications-Related Research Needs in the Education of the Severely Handicapped

Henry Leland

Nisonger Center
The Ohio State University

Fourteen years ago, the Congress of the United States established a program which granted qualifying institutions $100,000 a year for a potential total of 10 years under the broad heading of Hospital Improvement Programs (HIP). All of the participating institutions did not receive the total amount nor were all the participating institutions involved for the full 10 years. Yet by the time I lost contact with the program, in excess of $100 million dollars had been spent on research and demonstration programs associated with HIP grants in over a hundred institutions for the mentally retarded. The participating institutions wrote quarterly reports, annual reports, final reports. Typically 10 to 50 copies of these reports were forwarded to Washington, where one presumes they were properly indexed and stowed away for future reference and use.

As most of you know, before I came to The Ohio State University, I had spent 12 years as a clinical psychologist working in research on the mentally retarded at Parsons State Hospital and Training Center in Kansas, which had a Community Transition Program funded by the Hospital Improvement Program. The Parsons Project included sheltered-workshop development, vocational training, and other programming geared to eventual movement into the community and also the eventual development of the now-famous MIMOSA project under the direction of Dr. Lent, who is also with us.

When I came to the Nisonger Center, I participated in the development of a research and demonstration project which involved a vocationally oriented training program for retarded adult males (under the direction of Dr. Parnicky who is also with us at this conference). In the preliminary literature search, an effort was made to find those HIP programs in which the problem of vocational training and related topics had been researched and demonstrated. Requests went to Washington

for program reports from those institutions at which that type of work had been done. At that time, Parsons' name was not mentioned since the request was a general one asking for all reports on vocational training. The Parsons report was not included in the returned information. Evidently, the appropriate key words under which this material had been filed--or whatever system is currently in effect--did not produce the stacks of material from the Parsons project.

Now this is not a game we are playing. The Parsons material is obviously available if somebody sends in and asks for it, but it is patently absurd to presume that every researcher starting a new project is automatically aware of all the centers that have previously worked on a similar project. This is the purpose of a storage-and-retrieval system. This, presumably, is why so many copies of these reports had to go forward to Washington and how the tons of paper involved were used. This example leads us to some very obvious questions: What happened? What other programs were not included in the information received? What are the nature, faults, and remediation of the present storage-and-retrieval system?

I have to admit that in developing this particular talk, I found that I was faced with a most difficult task, not because there is not a great deal to say about the question of communications as related to research needs but because everything that we do is very closely related to communications. How to divide the general "concept" of communications into components related to major research issues became for me a very confusing problem and one in which there was an overabundance of anecdotes and examples but relatively little solid information. It appears that the major issue in communication and related research needs is that on a broad, simplified, practical basis, there almost isn't any.

Therefore, I have decided to try to identify three major areas of the communications problem which I consider most salient and most important to the task before us: the problem of data collection, storage, and retrieval; the problem of communication between funding agencies, research groups, and projects; and the

problem of communication between the individual researcher or the research team and other researchers and research teams as well as the public.

Data Collection, Storage, and Retrieval

The term "data bank" has been used with a variety of meanings. As efforts have been made to do this type of "banking," it has become increasingly obvious that while we are gradually developing the hardware for such a system, we have yet to develop efficient methods for the exchange of information as part of our ongoing procedure. When we look at the actual data collection, we are faced with the problem of collecting data that are easily codified for storage. This need for codification, while an excellent and important part of rigorous research, nonetheless could limit research creativity in problem definitions--if we could already define the topic clearly, and clearly identify all questions, we really wouldn't have to do the research in the first place. This is particularly true when we begin to look at questions regarding a population like the severely handicapped because the outstanding characteristic about such a population is that it has no unified characteristics. Current codifying and organization methods do not permit replication of research by quickly and efficiently finding what has been done, with whom, using what materials and what kinds of settings, and so on, and this need for information creates what now seems to be an almost impossible task of data accumulation. The result is that we collect "name, rank, and serial number" type data. It is easy to agree that we have certain ages or certain sexes, so this material is easily recorded and fits well into various computerized systems. But when we begin to look at the major data question with a population like the severely retarded, which for our purposes centers upon alternative behaviors, we are constantly faced with the issue that such material is either impossible to record or, if it is recorded in a specific setting, there is no way of transmitting it without sending volumes of ancillary and explanatory data. I am particularly alert to this aspect of the problem because in our efforts to develop the expansion of the Adaptive Behavior

Scales, one of the outstanding issues which has plagued us in trying to do behavioral measurement for the purpose of evaluation is that we have what I have described as an ocean-and-shore problem--that is, if you have less ocean, you have more shore, and the tide comes in and you have less shore and more ocean. When the severely and profoundly retarded do not complete a task on a measurement instrument, it does not mean that they are completely functionless, it just means that they did not complete that specific task. Instead of completing that task, they were doing something else, and the problem of recording what they were doing instead of the task (which is really the more important question) is typically totally ignored. In fact, in my own efforts to develop the Adaptive Behavior Scale, this question also had to be ignored in favor of a scale that is short enough and is efficient enough so that it can be readily administered and scored. But, if we really are talking about banking of behavioral data, we must look at these alternative behaviors when we are talking about expanding more careful research in the area of the severely handicapped. We need to know what it is that person is doing instead of what he is expected to do. It seems, on the surface, simple enough to record those kinds of data. But when one begins thinking of the horrendous problem of recording those kinds of data from all areas of the United States and putting them together into some central data bank so that we can begin to get an idea of the commonality of alternative behaviors, we really underline what has been one of the major difficulties in setting up any kind of data-collection system which has ongoing functional utility.

Presuming that we can come together in a sufficient fifty-state-plus kind of body and gain sufficient agreement on the kinds of data we will be collecting and the kinds of ways we will be codifying and recording these data, we must then ask how and under what kinds of circumstances will we store it? Actually the issue of storage appears to be less problematic than either collection or retrieval. Here,

it is a matter of arranging for the compatibility of equipment, the exchange of computer programs, general agreement on storage mechanics, and so on. These are primarily hardware questions.

Obviously, once a real agreement on what is to be stored has been reached, there is enough technical know-how that storage could be accomplished presuming that the various research organizations (the people on whom we are dependent for data) have access to appropriate storage centers. Clearly, we cannot lock ourselves into the situation in which only the large universities or large research centers that can maintain their own computers will be the ones doing the research. We realize that much valuable information and many valuable research teams exist in areas that may not be large enough to maintain this kind of equipment or even to hire and maintain the technicians required for the use of this kind of equipment. So that while the mechanics of the storage problem would seem to be the only issue at this state, these mechanics have a tendency to define who is going to do the research if the accessibility of this type of equipment becomes a requirement in the communications system.

Further, if we speak of some sort of central storage in either regional "banks" or some such similar arrangement, we then have the additional question of what stage of findings should be stored. Are we storing only final reports or are we storing the ancillary information, how will other research teams know what information was gained, what information was not gained, what errors were made? I realize that this kind of communication is not going on now but that is, I assume, one of the reasons that I was asked to give this talk, because we are not interested in how we can do more efficiently what we have been doing wrong, but rather how we can start doing some things a little bit more correctly and a little bit more effectively. Thus, one of the major questions is: How does a research project communicate the anecdotal aspects of the research experience so that we do not need to be constantly reinventing research wheels but may literally pick up where other projects left

off, or if we have some question about their findings, effectively and efficiently replicate their material to see if we can discover where the slippage occurred? The question of how to store that kind of information is one that I have not even seen approached in the literature about data banks and their usage..

Finally, we have the problem of retrieval. Having stored the material, how do we get it out for distribution and usage? I hope we have all grown out of the old notion that research is its own reason for existence and that we don't have to think in terms of possible application of results and continued usage of data. That era in research probably served psychology valuably, it helped set up a rigorous system, it put appropriate emphasis on design and method, but I think now we have sufficiently come of age as a research-oriented discipline that we can honestly say that the only efficient use of research monies is to look at a problem that requires investigation and having completed the investigation, either successfully or unsuccessfully, to report that information so that applied practical programs may be derived from it. The sending of magnetic tape all over the country so that various research teams can spend too many hours working over raw, unorganized statistics does not seem to serve our purpose. Nor does the mere distribution of final positive reports in our journals serve for replication or practical programming purposes. The efforts to set up data-retrieval systems have typically been centered on the need to make public reports rather than the need to exchange the kind of data that would further longitudinal or geographically dispersed research interests. In addition, we have yet to differentiate the needs for technical exchange between researchers from the need for exchange between researchers and the public. Modes and methods have to be devised whereby researchers may communicate with each other on the material that they are investigating via computers or data-bank networks, recognizing that the need for this kind of technical exchange is different from the need for the mere retrieval of final results for further research or public usage.

Communication between Funding Agencies, Research Groups, and Projects

I think that we can summarize this issue relatively quickly by simply pointing out that while the federal agencies are under a broad heading of Health, Education and Welfare, most of the states are separated into discrete departments which not only do not exchange information but often don't even talk to each other on a friendly basis. Each of these departments receives various types of research funding, often from a central federal agency, but as this money filters down through the regions and the states, it gets dispersed into groups that do not communicate with each other. There is usually an effort to make sure that two agencies in the same location are not researching the same subject. This is not really the answer to the question, however, because quite often they may be collecting, or have access to, data that would support each other's research topics even though they are measuring different aspects of them. Everyone doing research with the severely retarded should be in a position to know other persons in the same general locale who are doing research on that same population or persons in other locales who are conducting similar investigations. There are various efforts going forward to develop consortiums of agencies and persons involved in similar goals, but suggestions for research consortiums typically fall on deaf ears. There seems to be a fear that if one has a research consortium, there will be stealing of ideas or possibly the stealing of copyrights, and so on. Therefore, research workers feel they have to function with their material very close to their chests and often will not even fully communicate the important information within their own agency, much less share it with a neighboring agency or another state.

One can recognize that two motor companies might not want to share secrets since they have to make a profit and the one that can come out with the most efficient engine supposedly will sell more cars. But that is not the basis for publicly supported research. We are dealing with public funds; we must have some sense of social awareness and public responsibility. To speak from within the confines of my own "bag," we have to demonstrate some sort of effective social-adaptive behavior. And

it is patently absurd to permit a situation in which two or more research teams may be investigating the same general area without sharing the information. Obviously an unlimited number of research teams may be called upon to investigate a broad generic topic recognizing that there is no specific philosophy nor a specific way in which a topic should be approached. In the long run, the research information is going to have to be completed before conclusions can be drawn. Conversely, if public monies are being used, these teams have a responsibility to share some of the broad lines of what they are doing and, if possible, to work out the best way of tackling the topic (recognizing that there is more than one experimental method and that all methods have a right to be tested). The public has a right to the best and most valid approach that can be derived. Further, if the work is being done with a practical goal in mind, the public has an additional right to have this information as rapidly as possible because in addition to the integrity of the researcher and the autonomy of creative thought, we have to recognize that human lives are involved and affected and regardless of where else we stand, that fact must take precedence.

To summarize this issue, it is a matter of finding that fine line between protecting the integrity of the individual research organization, protecting the creativity and innovations that are required to open informational doors that have previously been locked, while at the same time recognizing that we are talking about severely and profoundly handicapped human beings with human rights and we cannot continue to permit ourselves the luxury of putting our personal feeling for autonomy and competitiveness ahead of those human and personal rights. While it is not my purpose to lapse off into a discussion of ethics, I feel very strongly that one of the greatest safeguards of human rights is the continuous and open communication process so that everybody involved knows exactly what is going on, what is being accomplished--and more important at times--what is not being accomplished.

Communication between the Individual Researcher and Other Researchers and the Public

When I was starting to prepare this talk, I asked my students what, in their opinion,

my major communication problem was. They acted as though they had been waiting for me to ask that question: They immediately came out with a long list of things which indicated that I work from a very clear-cut, philosophical system loaded with various kinds of biases, that I discuss research in a "personal" vocabulary, often speaking from private information and knowledge of private variables, that I often use a code language in lieu of careful definition of terms or when I do define terms, I define them in a personal way different from that in common parlance. In other words, they were telling me that as an active research person, I had developed a personal lore with many built-in biases and as long as they were fully acquainted with all of the previous research that my organization had done or that had been done by persons associated with me, they could follow what we were talking about but that when they were not privy to that communication, they often did not get the full meaning.

Now I don't think I am unique in this style. I think that any one of you in this room would get the same response from your students if they felt comfortable enough with you to be completely honest. Moreover, I am sure, in terms of the group I am speaking to today, that you have those kinds of students because that is the life blood of an effective research organization. It occurs to me that this is probably an expected component of research procedure. Over the last few years, we have been rapidly putting away the myth of strictly objective research which can be performed independent of the ideas, feelings, and philosophies of the researcher. We have become increasingly aware, particularly in doing research with human subjects, that the bias or set with which we enter the project has a great deal to do with the type of outcome. This bias, this use of personal definition, this use of private information, becomes part of the "lawful" process of our behavior, and since we are doing the research, it becomes part of the "lawful" process of the research. It is apparent that if this is part of the process, then the realization of the existence of this phenomenon should be written into the research design. It

should be a necessary component of our whole communication system, and our colleagues and other research groups should know where we are coming from, where, in the modern parlance, our head is, in regard to the particular research which we are doing and the particular interests and personal investments that we have in that research. It is both artificial and impossible to pretend that we are doing research without personal investments or individual motivations, and it is the height of hypocrisy to further pretend that our results are totally objective and independent of philosophical or bias loadings. Further, I am not too sure that this is an unfortunate state of affairs. I am not saying that we can assume the guru position that we are the senior people, that we know what should be happening and that our biases, sentiments, and so on are the last word in research procedures. Rather, recognizing that everyone, no matter how junior or senior, has a frame of reference, we can insist that part of the understanding of research is a definition and statement of those frames of reference. We would all be in a much better position to understand how certain kinds of results are derived, what kinds of expectations or predictions we may make concerning research situations, and what kinds of additional safeguards have to occur to insure that we are actually finding what we are pretending to find. In addition, I feel that the expansion of this kind of communication should include the development and broadening of the total concept of the research methodology to include human subjects. It is not enough to assume that human subjects are bigger than our laboratory mice or merely have a different biology than some other anthropoid subject; we must recognize that first and foremost, they are <u>human</u> subjects. They have the rights of human beings, they have the fears, the joys, and even if they are severely retarded, they respond to these fears and these joys, and the interaction between these subjects and the researcher may in the long run be the most important aspect of the total research effort.

Obviously, I am not saying that use of a private language, the regarding of private information, the failure to properly define, are excusable ills. They are not. As we expand our communication with our peers, with our colleagues, with the

community to whom we must report, we must make an effort to be sure that we are understood, that we are in essence using common language, and that the things that are pertinent to the problem at hand are exchanged on the most open basis possible. Part of the problem is not only that we are dealing from a subjective personal bias in most instances but also that we are dealing in scientific jargon. There seems to be a research snobbery which says that the English language isn't fully useful for research purposes and that we must talk all around the issue rather than calling a problem by its own name. The efforts to communicate are thought to be only truly scientific and truly successful if they are written or expressed in such a way that only the elite can fully understand the results. We seem to feel that if we are fully successful in doing this, we will have protected ourselves from attackers who are not part of the elite and therefore are unable to attack us because they don't understand what we are doing. In this way, we guarantee that the mysticism which surrounds the research scientist will somehow protect us from the harsh attacks of an unknowing philistine society.

Our current experience with research funding and allied problems demonstrates that this approach to communication is not only unfortunate but extremely stupid. In the long run, it has cost us many important research projects and many thousands of research dollars. We have to try to put our plans into the most understandable and recognizable terms so that everybody will have some idea about what we are doing. It is certainly possible to translate information into language that will permit a congressman or state legislator, a school board member, or a parent of a child being asked to give consent (let's not forget the question of "informed consent") to know what we are doing, to understand it, and to agree that it is both useful and important.

What comes under the heading of Identification of Communication-Related Research Needs in the Education of the Severely Handicapped? I don't really feel that I have discussed that topic though I have certainly talked around it. I have not discussed the topic basically because, in a sense, it is a research need itself.

Since the election of President Kennedy, we have spent over 15 years involved in varying levels and varying quantities and qualities of research. We all can look back and say that we have not really dealt with the communication aspect of this. We have met at meetings of the AAMD, APA, CEC, and other such organizations. This type of professional communication is extremely important but it is not the kind of communication needed to fulfill research needs. What kind of communication between professionals is most needed to produce efficient, public-serving, science-serving research that will enable us as investigators or as teachers of future investigators to best serve the interests of the severely handicapped, helping them develop to their fullest possible potential, in keeping with the provisions of the Declaration of Rights of Mentally Retarded Persons?

We cannot separate our responsibilities as scientists from our responsibilities as people. Communication seems again to be the most genuine and effective means of maintaining our responsibility to society. We cannot continue to back away from communication problems, nor can we continue to spend public monies in promiscuous ways, using the existence of communication problems as an excuse for ignorance of other research or how other monies are being spent. Or, more simply, ignorance of whether we are actually making the kind of contribution we should be making to the habilitation and rehabilitation of the severely handicapped.

I opened with the question of what happened to the HIP data. I am going to close with a question of what has happened to the data from all the research efforts that went forward during the sixties. While I don't have ready-made solutions, I would like to suggest we take a hard look at that question and how we might salvage the situation. One possible answer might be the development of more generic categories so that information could be banked in concept groups and specialized banks. I am aware that often the cost of exchanging materials makes such cooperation impossible. But, whatever the means, we need to settle down and begin to tackle the question.

In summary, then, I have tried to underline three communications areas of concern: the problem of data banks as represented by the gathering, storage, and retrieval of information, the problem of inter- and intra-agency communication, and the problems of personal communication between the individual researchers. I have tried to put these communication questions into the context of the special needs of research communication and the special and ethical needs of maintaining an honest communication with our public so that the rights and humanity of our research subjects can be protected.

TASK 4:

Identification of Management/ Administration Research Needs in the Education of the Severely Handicapped

Remarks

by

James Budde

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My talk is divided into three parts. The first is concerned with the problems of management in human services; the second has to do with some research ideas I think we ought to consider; the third has to do with some initial data we have collected in a research program directed at the management area. I will point out some of the mistakes that are happening in in-service systems and I hope you can laugh about them because some of the mistakes that I will point out are ones we have all made in the past.

Problems of Management in Human Services

We think of ourselves as being a power country, a country that has a lot of technical reserve that can be used to develop numerous resources to solve a number of problems. There is no doubt about it. This country has accomplished some great feats in its time. However, the side effects of some of those great feats that have resulted from poor management, because we were not careful about looking at all parts of the problems, plague this country today. You see the problems we have in our cities with pollution. We can walk on the beaches and see the ecological problems we have and we don't have to go very far to see our surging economic problems. However, the area that we are concerned with most at this conference is the education of the handicapped. We are concerned about a population that cannot speak for itself, a population that cannot control its own destiny. Therefore, it becomes our responsibility as researchers, service providers, and managers to deal with problems related to that area. Research's potential for solving problems should be used to eradicate or impede problems related to the handicapped.

We have used our technology to produce luxurious automobiles with sophisticated evaluation systems. Instruments tell us how fast we're going, they tell us when something is going wrong with the automobile or what time it is, they make it easy for us to steer and to stop. There is even cruise control that drives your car for you. About all you do is steer a little bit once in a while. But when you start driving the human-service vehicle down the road of human need, there is no such sophistication. When designing human-service systems, we find it much more difficult than developing the blueprints for an automobile. These systems are complex and we are not using our technology to reduce the complexity.

How does the human-service administrator plan a human-service system with a group of people? What happens is that he has a number of people in the group that he has to be concerned with. He has a politician who's trying to make his mark. He has the intellectual who is trying to let everybody know he is the smartest one in the group. There are other people who completely ignore him, and there are a lot of actors, just as there are in the real system. The task is to take all of the input from these individuals and try to use it to develop a management system that will help the handicapped. If the manager is not equipped, if he is not trained and doesn't have the proper tools and techniques, what he usually does is to withdraw to a corner and start with the only planning tool he knows--a budget and a table of organization. He draws and redraws the table of organization, careful to balance positions and salaries in order not to offend anyone. (If you don't balance it out, you are going to make people mad.) Often, managers keep on planning, considering only individual status and salaries of staff, and it is often assumed that services to the target population will be provided some way. But we often forget about the service and the welfare of those to whom we are responsible. How good is this traditional planning?

Then, too, there is the manager who says he will do all things for all people.

"We can't provide all services for all people. We don't have enough resources," says his staff. The manager says that he can't get any more resources, that they'll have to make do. Often managers who do not plan accurately are subjected to statements like "If we give you more resources, you'll just overspend, so we'll have to make you efficient by giving you less money." What kind of planning is this? We must be able to specify what will be achieved for certain amounts.

And then, of course, there is the communication problem, which happens in all organizations. Usually what happens is that somebody does something the boss doesn't like and he says "I think we're having a communication problem." The problem was probably caused by his not explaining what he wanted done in the first place. If we are to have effective communications systems in our human services, we must first ask the question "What tells us that we are meeting the handicapped's needs?" and the second question, "Who should know this?" and the third question, "How do we get the information to these people?"

So what have human services emerged with as managers? The hipshooter is one example. He starts work perhaps as a social worker, as a psychologist, maybe an educator, maybe a researcher, maybe even an auto mechanic. And all of a sudden, the Peter Principle has gotten him to the top. He finds himself confronted with a multitude of critical incidents that are closing in. Bang! Bang! He shoots from the hip, trying to eliminate those critical incidents. If we have managers who are using good management sense and skills, we don't have to solve the critical incidents. Good planning, good programming, and good spending go a long way. Such practices prevent us from being on a course that requires us to crash into programs to solve critical incidents. Often, we don't even know if some of our crash programs are working or not working. We don't use evaluation systems like the ones in our automobiles that provide us with a little red light to tell us when things are going wrong. For the most part, the research that has been done in the area of management of human services is pretty much like that done in the cave man era.

What is Government's answer to all those problems? It's called accountability. What I'm suggesting is that accountability is not needed if you have good management. You don't need accountability. You have it.

Some Research Needs

Little research has been done on management for human service. At the Kansas University Affiliated Facility (UAF), some of my colleagues and I have used research to develop a type of management that is reactive to the needs of the handicapped and a system that is also effective, economical, and self-improving. It is called formative management, an approach that is used to study and control human-service behavior and to mold and shape the service behavior as you would for a child so that he can develop to his optimum. We determine the behavior of an organization that is used to eliminate need and mold and shape that behavior in a similar way.

Much of our work started by using model-building techniques. The traditional model we see in most human services is the table of organization. As a matter of fact, we sometimes see it used in archaic businesses that are going broke. The input for this model comes in from the top. In the federal government, it starts through legislation. If you have ever been in Washington, you have seen politicians working on committees. They and their aides work very hard trying to develop information that they can use to draft legislation. The problem is that the system is supposed to pick up information to meet needs before needs become a problem. Where is the marketing approach? It seems that the model starts with power, not with need.

When legislation is passed, of course, it becomes the responsibility of the federal government to carry it out. Federal agencies talk about what the money should be spent for and they develop regulations that accompany it. I think that federal agencies are often hampered because they do not have the kinds of management

information that they need in order to develop these regulations. Federal agencies are removed from the operational level, and it is difficult to view the problems at first hand.

Finally, disbursement of money is spread across departments. The spending goes into three areas: 1) direct services; 2) support services; and 3) research. Government feeds monies into these areas, and ways to cut across and coordinate these efforts just don't exist. In fact, it is not unusual for various branches of organizations or states and certain agencies in government to not talk to one another. In some cases, staff members of such agencies will say with pride that "We don't work together." Perhaps the new concept of partnership grants in government will help with this problem. Perhaps mechanisms like the systems approach in the space program or the interdisciplinary approach in medicine can be developed to solve common human-service problems.

At any rate, I think we ought to look at other models. The kinds of models that were used to put a man on the moon, for example. By 1938, all the principles had been advanced that were necessary to put a man on the moon. We didn't do so until there was a commitment and management resources to carry out such a feat. I'm not sure human services are not in the same kind of a situation today.

Let's take a look at a different kind of model--a business model. What would human services be like if they were evaluated like production lines that produced human-service units? If production is down, business is considered to be failing. In this instance, research is used to improve two things: 1) What is happening to the product--the quality and the economy--and 2) What is going on in support services to enable production to occur at an even higher rate with equal or higher quality at a cheaper cost?

We also have to review old models that have been misused. I admire Confucius who said that every time a government agent makes a decision, he should take into account the needs of those he serves. Who considers the needs of the people in

our management decisions today? I'm not sure we're aware of needs. We give lip service to them, but I'm not sure we're really aware of them. Of course, being aware of needs and doing something about them are two different things. When we run into complexities of human-service organizations, we forget about need. We could solve the problems if we were to zero in on products or service units that meet needs. We need to find new methods through the use of research to define and measure products. If we cannot measure products and cost, how do we know how much is needed to do what?

Research should be used to solve real problems in human services. If researchers are up in an ivory tower too far away from the services, they won't make advances that solve human-service problems. They'll have nothing to build on. Functional research organizations are those that work in the field solving real problems. From the management standpoint, we not only need research on direct human services but on support services as well. How can we provide better support services to improve direct services?

The Human-Services Continuum

So, let's talk about management and marketing. Let's talk about the complexities and possibly some of the things that can be done. One of the things we need most is to know who the consumers are out there and what they need. If we can't do that, we will fall short before we start. Once the needs have been determined from marketing information, comprehensive programming must be conducted. People talk about comprehensive programming, but few define it. Comprehensive planning is seen to be something that is a monster and it need not be.

Choosing the best approaches is another research problem. For example, special education or regular classes? Actually, there are numerous alternatives; a whole continuum of alternatives. What we don't do is look at various approaches on the

continuum. At one end of the continuum, we have a number of people who are in custodial schools (if you can call them schools), although we have laws that handicapped children must be provided with education. Further up on the continuum, there's an area that is being developed which is called a segregated school. A number of people have asked me about the segregated schools for the handicapped. "We just passed a bond issue," they tell me, "and we want to build a school because it's been mandated now that we provide education for the severely handicapped. So we're going to build this beautiful little building right beside the regular schoolhouse. What should we put on the inside?"

Shouldn't research answer this question? But perhaps the question is wrong. How can regular classrooms be remodeled to serve this population? With decreases in enrollment, classrooms could be made available for this population and architectural research is needed to remodel the inside of the school so that it can be adapted to the special needs of a child. We don't need an institutional school outside of our regular school system; there are better alternatives. I think this is a major research need that we ought to be working on. We're talking about mainstreaming. Are we going to mainstream from one institution to another institution?

At any rate, there is a continuum to education that includes segregated schools, special schools, and integrated schools where some handicapped youngsters are taking regular classes. Of course, at the higher level, we have the support services that meet special needs and maintain the child in regular classes.

There is also a living continuum. At one end of the living continuum of alternatives, we have people in institutions and nursing homes. What are we going to do to get them out? What does a manager do to set up new alternatives? Is research telling him what the alternative program is supposed to be like? When it comes to important research questions, one of the most critical is: How do you beef up the services to help the persons who are at the highest living or educational level to keep them there? How do you prevent institutionalization? What do you do

to keep the child in his home? What kind of parent training program is needed? How can a child who is severely handicapped get medical attention from a regular hospital instead of an institution that may be down the road 30 miles? How do you combine services and manage them? What works best? Those are key management research needs.

Another continuum we have is in the occupational area. At one end, we have a work activity program. People are sitting around doing little if anything. Again, what are our alternatives? One of the interesting things that ENCORE (Eastern Nebraska Community Organization for the Retarded) is providing as an occupational alternative is the work station in industry. They are enabling the handicapped to develop their potential in a work station within the normal environment of an industry instead of in a sheltered environment. Now I admire ENCORE for implementing the work stations. The work that has been done to develop this idea in industry has been quite good. ENCORE, I believe, has six work stations. Where is the research that told them what kinds of procedures they needed to use to set up the work stations? What are the program procedures? In this case, the human services are out in front of research and they did determine need.

We have to deal with economics. Today, human services make up almost 50 percent of the Gross National Product. If we can't find a way to make our human-service systems more economical, we are going to have to cut them out or go broke in the process. When human services get so heavy that tax dollars can't support them, we won't be able to afford those services. So, we have got to find ways of making services more economical without loss in quality. One approach is for management to set up alternatives that would keep the children in normal homes.

But that's not the end of the management problems or research needs. When your human-service administrator sits down with a table of organization, the human-service system seems very complex and difficult to define and constantly changing. You need new tools and techniques to define and measure such systems.

Management Tools and Techniques

If we were to study the history of architecture, we would find that pieces of houses 600 years ago did not fit together very well because there were only crude blueprints. Until blueprints were developed that illustrated the dimensions of the pieces and how they were put together, the building process could not be controlled. It was no different with medicine. Until physicians understood how the inside of the human body functioned and diagrams could be drawn like a blueprint, fatal practices such as bleeding were used. The only blueprints traditionally used for human services are tables of organization. Where are the manager's blueprints for programs to build a child? This might seem complex or unethical but there are researchers who are developing such blueprints! There are other researchers who are developing blueprints for programs to specify what the learner is to know and how to get rid of duplications and gaps in educational services. Such behavioral engineering is not new.

Another critical need is in the area of evaluation. Where is our red light that tells us when something is going wrong in the organization? How does the manager get his system and staff back on the road? When the red light in an automobile comes on after the fan belt breaks, you stop before something else critical happens. You deal with the problem immediately. It's possible to detect problems in human services in the same way and to prevent massive problems.

Human services need better measuring tools. One of the areas we are interested in is how to write what we call second-generation measurable objectives. Present methods do not always result in measurable products. If you do not have measurable objectives, even if the criteria are somewhat loose, you can't take the first step in implementation or evaluation. Without measurable criteria a manager has nothing to measure performance against and he has no way to evaluate the performance of that component of the human service. We need to be concerned with cost as well as performance. We need to be concerned with time and how well we meet deadlines.

And there are tools and techniques for this purpose; I don't know if these should be researchable areas. It is questionable whether we ought to spend money in an area where there are enough practical applications in human-service systems and management to answer the question. We might, however, need to use research to improve the tools and techniques.

One of the other areas I'd like to talk about in management research is the need to integrate information at all levels within human services and government. Industry in this country doesn't handle this one well. The Japanese, in their management systems, probably get about 30 percent more performance out of their employees because they involve them in management to a higher degree. How do you involve employees in the management process to improve human services?

When it gets down to ongoing management, there are two key issues. The organization must be set up to control cost and performance. But what are the products of a human-service system that are used to measure performance? There's a good research question. What are the products? Furthermore, how do you define what the products of an organization are so that you can measure performance? And once you start measuring them, how do you get performance up, how do you maintain it at a high level? Once you maintain a high level of performance, how do you bring the cost down? Human-service administrators and staff don't make a bigger profit if they bring costs down. They don't make a bigger profit if they bring the performance up. So why do it? Perhaps the contingency system or reinforcement system is a major problem. There's another research question: How should the payment system be changed? Should there be another form of payment? Based on performance?

And the final question we are working on in our group is that of feedback. How much of the performance- and cost-evaluation data should be fed back and how often in order to improve cost and performance? What is the simple way to explain the results to staff? Finally, if we get enough of the right feedback, it's much

easier to make a decision. One of the hardest problems for groups like ours today is that we don't have enough information to make decisions to set good priorities and needs. It's not that we are bad decision makers, it's just that the information is not available. We don't have any marketing information to help us make the needed decisions. Therefore, it's much harder for us to say what research needs are than it is for General Motors which sees its market going down because its cars don't get 30 miles to the gallon and they weigh 4,000 or 4,800 pounds.

Data We Have Collected

I'd like to discuss some of the data that we've collected in our research from human-service organizations and from one of BEH's research projects. The first service is a technical assistance network that operates across a four-state area and is designed to train people to improve human services. In order to measure the impact this system was having, we had to define the service products. There are 16 direct products that can be provided. They all have measurable criteria. During the first year, we developed a baseline to see what was coming out of our system. We provided 221 products during the first year and so we had some data to set our objectives for the next year. Our objective was to go out and next year provide 260 products in this four-state area.

To project product or performance trends, we need to look at frequency. We see that in September, October, and November we were low in performance (products provided); that was when we were getting started. The momentum picked up in performance and then dropped off toward the end. There is also a seasonal cycle and you see it in both years. Who says human services don't have seasonal cycles?

Cost is another problem. This is something human-service managers typically don't deal with except when the budgets go in. We find a very interesting thing in the data we have collected. And it's not surprising. In a three-months period there was a dip in services during the second month and the cost per unit just went

out of sight. If service products are provided less frequently, overhead is the same and cost goes up.

Another very interesting thing that we're finding is that in human services almost 50 percent of the budget goes into indirect services to provide direct services. In some instances, in the early development of a project, it goes beyond 50 percent. Seventy percent has gone into support services. This changes from month to month. Research need: Where are the tools to be used for administrators to control the mix of services, both direct and indirect? How do you measure this?

The concepts of cost effectiveness and cost benefits have been around for a long time. But few managers of human services know how to use them. We are now checking to see what kinds of things we can do to the system to bring the costs down and increase the performance at the same time. One of the things we are pleased about is that we are at a point where we can measure performance and control it. Again, these things are in the initial stages but are starting to prove out.

At the beginning of last year, we projected a line for performance and cost dimensions. Products were specified on systems blueprints as research steps were defined. The research steps on products were later refined with measurable objectives. In order to reach our objective of completing a certain number of products by the end of the year, we had to measure against the cumulative curve which was projected at the beginning of the grant year. When we started out working, we experienced a thing called an "airplane effect." During the first few months, performance was low and costs high. Performance and cost were brought into line by the third month and even improved beyond the projections. This went on until the fall when we were in the process of writing new grants to continue the project. You'll note that product performance came to a standstill. I think that's the first piece of data I've seen that illustrates what happens to the performance of a research group when grants are being written.

There are various kinds of activities that a manager requires staff members to work on. One is setting up the management-information system which we sometimes call an accountability system. At first, most staff complain that this activity takes too much time. In the beginning, setting up the system took about seven percent of the staff's time. After that, it took about four percent. That compares very favorably with the management data that I have which is running about two and three percent once the system is set up. Evaluation doesn't cost as much as one would think.

Now I have talked about specific needs and given specific examples of what research is needed and what can be done. You will need to expand the areas of 1) marketing or needs assessment; 2) performance and cost planning; 3) feedback and communications; and 4) humanization. Will we use research to solve existing problems through practical application or will we confine ourselves to an ivory tower and conduct statistically pure research that has little relevance? If we cannot identify functional needs, we may well confine research to the ivory tower and we can't afford that as long as human suffering continues.

RECOMMENDATIONS

The Steering Committee for the Conference on Education of the Severely Handicapped identified four topic areas for which research needs were to be developed during the conference: goals, service, communications, and management and administration. In addition, they outlined 10 categories of emphasis. (See Figure 1 on page 5.)

Thus, there was a 4-by-10 working model for the conference: Participants were divided into 10 working groups, each one concentrating on one category of emphasis as they identified research needs related to each of the four topic areas.

Although the model was useful as a framework to structure the conference, the participants did not feel constrained by their group assignments. In fact, their recommendations for research cut across categories and even beyond the purview of BEH. Relatively few recommendations related solely to a given category or focus topic.

The top-priority needs for research are given on the following pages as they were reported at the final conference session. They are accompanied by related statements that had been reported by the groups during the preceding sessions. The discussion of the top-priority needs begins below. The discussion of the additional research needs the participants identified as critical but not top-priority begins on page 83. Each research need is presented as a question and is followed by a specific recommendation (or recommendations) for research. The topics included in the top-priority and additional research needs are not listed in order of priority.

I. The Top-Priority Research Needs

Prevention

The participant group concerned with prevention recommended a two-part approach for research.

1. Develop programs and train personnel to counsel and educate school-age children so that they may:

   - Exercise reasonable control over their own destinies with respect to the decision to bear children and the circumstances under which they bear children
   - Prepare themselves to be effective parents
   - Develop understanding of the causes and consequences of handicapping conditions and greater acceptance of handicapped persons so that they may seek appropriate care early in pregnancy and help for their child should he or she develop a handicap

2. Develop programs and train personnel for early intervention that is oriented both to parents and infants, beginning soon after birth and continuing through the first year. The programs should focus on:

   - Infants identified as likely to develop severe handicaps
   - Infants with handicaps which may be ameliorated so that the associated problems are less severe or are held constant

What parent programs are most effective?

Study cultural diversity among parents (of both handicapped and nonhandicapped children) to determine the range of alternative practices by which parents may adequately care for, accept, and seek care for their children.

Study the longitudinal effects of the following kinds of parent programs:

- Within the general education system for preadolescent and adolescent students
- Special education and counseling for prospective parents, especially high-risk mothers
- Education counseling for parents of high-risk and handicapped infants

Evaluate the impact of parent programs on the development of skills for family planning, utilization of prenatal and obstetrical care, utilization of services that are available for handicapped children, incidence of severe handicapping conditions, and the improved capacity to understand and care for a handicapped child.

How effective are early intervention programs in preventing or ameliorating handicaps?

Determine criteria for measuring the effectiveness of programs on the overall development of the child (short- and long-term effectiveness).

Study the effect of these programs on the incidence of severe or multiple handicaps.

Study the effectiveness of different treatment methods for children with various kinds of handicaps.

What are the barriers to providing early intervention services?

Study the effects of diverse staffing patterns and personnel backgrounds (academic and experiential).

Determine the availability of qualified personnel.

Determine the effect of costs, funding patterns, and cost benefits on the availability of services.

Study barriers to effective communication among medical and educational personnel and the family of the handicapped child.

What are the most effective criteria for selecting children for early intervention programs designed to prevent severe handicaps?

Design methods to identify those high-risk infants who can be benefited by early intervention efforts.

Determine how best to obtain acceptance of and cooperation in the programs by parents and other members of the handicapped child's family.

Early Identification

At the present time, there is no comprehensive system to identify the handicapped and to provide them with educational-medical services. For this reason, one participant group, concerned primarily with early identification, recommended as the most critical need for research the development of a case-finding system that would include such critical factors as:

- An efficient high-risk schema
- Routine and efficient screening procedures

- Consideration of social and economic costs
- Medical and educational tracking

n we identify those high-risk factors that lead to severely handicapping conditions?

Conduct longitudinal studies integrating the findings of previous studies conducted in other communities and other countries.

How can parents and others help in the early identification of handicapping conditions?

Determine the most efficient system for education and training and for the transmittal of information.

Is it socially and economically feasible to institute programs for early identification?

Compare the social and economic costs of programs that are available to all families and those that are mandatory for all children from birth to age 3.

What system is needed to ensure that all severely handicapped children receive the necessary services?

Develop medical-educational models for tracking children after identification.

Investigate ways to improve communication among all personnel who serve the handicapped--medical, educational, psychological, social, and so on.

What are the barriers to the development and implementation of an effective case-finding schema?

Identify and explore ways of reducing such barriers as:

- Dysfunctional communications among consumers, researchers, and practitioners
- Professional personnel preparation and motivation
- Institutional roles

- Lack of a standard taxonomy
- Inadequate utilization and dissemination of existing technologies

Assessment Models for Diagnosis and Screening

In order to better serve the severely handicapped student, more effective programs for diagnosis and screening must be devised and implemented. Efforts to date have been largely fragmentary. Thus, the critical need for research in this area is the development of comprehensive models for assessment. The participant group concerned with clinical and developmental diagnosis and screening recommended that a task force be appointed to coordinate the development of specified kinds of models. They recommended further that a mechanism be provided for periodic assemblies of the task force to compare models, to evaluate their effectiveness, and to disseminate the findings.

What information is needed to implement and maintain effective intervention programs for the severely handicapped?

Assess how teachers currently use available diagnostic information for educational planning.

Determine what purposes can be served by diagnosis and screening procedures.

Develop frameworks (or models) to determine needs for assessment.

Develop assessment instruments and procedures.

Evaluate models for their effectiveness in promoting handicapped students' development and in assignment of these individuals to appropriate specific training programs.

Develop strategies for replicating exemplary programs.

Develop models for assessments that include input from such disciplines as ophthalmology, audiology, neurology, psychopharmacology, and orthopedics.

What sources of information are used in developing individualized programs for handicapped students?

Consider such sources as psychologists, medical personnel, educators, parents, and the staff of social and vocational agencies.

What is the optimal environment for assessing handicapped children? Which personnel are best able to do the assessing?

Consider cultural differences.

How can communication about the assessment process be facilitated?

Develop appropriate means for two-way communication on assessment information between those who diagnose and others concerned with the handicapped--parents, colleagues, teacher-practitioners, and the community.

Identify ways in which the personnel and parents who work most directly with the severely handicapped can provide input to the assessment process and can be involved in making decisions about program adjustments. Explore the benefits--and possible disadvantages--of this involvement.

Study the benefits derived from a system for determining whether or not field personnel are following procedures outlined by the assessment staff. The study should determine the impact of such a system on improving the implementation of recommended procedures and on better, more realistic recommendations by the assessment staff.

What kinds of administrative structure best facilitate effective assessment and programming?

Study effects of different structures on:

- Cost benefits
- Professional and paraprofessional personnel requirements
- New and projected technology
- Quality and effectiveness of assessments
- Effective communication among the parties concerned

Models of Alternative Service Delivery Systems

One participant group identified the top-priority need as research on the immediate and long-range effects of alternative kinds of service delivery systems

and the development of models, many of which should be future-oriented. The group specifically noted that the models should include fully developed and documented explication, validation, and dissemination strategies; they should not be merely demonstration programs. Another group identified the need for research that focuses on cost effectiveness and cost benefits of alternative delivery systems in different settings such as group homes vs. institutions.

What are the immediate and long-range learning effects of alternative systems?

Study the dimensions of service: care, treatment, training, and education.

Demonstrate whether or not behavior-modification techniques are effective or harmful.

Conduct longitudinal studies to determine whether or not the effects of the program are permanent.

Compare outcomes of programs that are designed for different age groups and types of handicap and offered in a variety of settings.

Determine opportunities for employment and community-living options to identify appropriate training for the severely handicapped.

Develop and validate a comprehensive data system for recording pupils' progress and assess the impact of the data-collection process on the teaching-learning process.

Develop and validate measures of teacher behaviors and efficiency in different instructional settings.

What sociological and political variables facilitate or impede the implementation of alternative service delivery systems within the community?

Study the effect on learning outcomes of alternative residential-educational environments for the severely handicapped.

Assess the role of direct-care workers.

Determine how sociological and political aspects of the community impact on the development of community-based programs.

Are there significant differences in cost benefits and cost effectiveness among alternative programs?

> Evaluate current management systems in different agencies, in different locations, offering different types of programs.
>
> Analyze the cost effectiveness of education and treatment of the severely handicapped in different settings such as state residential institutions, community-based residential homes, and neighborhood clinics. Determine the effects of deinstitutionalization.
>
> Identify more effective ways to utilize manpower and resources.
>
> Compare the efficiency, costs, and quality of services when funds are paid directly to the client rather than to the service system.

Information Exchange Systems

The conference participants noted time and again the inadequacies of present efforts to collect and disseminate information on research related to the severely handicapped. This lack of information results in long delays between the completion of research and its implementation. Frequently information on important research that is not published never reaches the field. Moreover, there is no systematic way to provide for input from the field into research efforts.

Three groups identified this area specifically as the top-priority need for research. One recommended the development of a researcher-teacher model for direct two-way communication between researchers and practitioners. Two groups were concerned with a large-scale system for the collection, evaluation, storage, and dissemination of information about products and processes. (It was noted that careful cataloging and evaluation of existing reports on products and processes will make it possible to identify areas for which there are needs for additional research, development, and dissemination.) Although the needs statements submitted by the three groups have slightly different emphases, there is considerable overlap among them. They are, therefore, combined in this section of the report.

What needs for communication do different consumer groups have?

Establish task forces to identify needs for information.

Determine the form and content appropriate to the purpose of communication and the intended recipients.

What effect does the flow of information between researchers and teachers have on pupil gains, on teacher behavior, on topics selected for research?

Investigate which models are most effective in improving interaction among researchers and between researchers and teaching staffs.

Develop new communication methodologies.

Develop models of communications systems for researchers and potential consumers of research.

Develop researcher-teacher models for evaluation and prescriptive programming.

What alternative formats for the exchange of information are feasible and effective?

Compare such formats as intensive conferences and audiovisual presentations.

Design, conduct, and evaluate programs for teachers, researchers, and funders to:

- Develop priorities for research
- Establish a common terminology
- Stimulate appropriate research
- Encourage applications of research findings

How can barriers to effective communication be overcome?

Identify a common basis for communication across disciplines for teacher training, multi-disciplinary research, and multi-professional service in the field.

Develop standard criteria for evaluating research products.

Develop a standard notation system.

Design efficient systems for information collection, storage, retrieval, and general dissemination.

What are the best ways to implement an information system?

Identify and evaluate information now in the system and sources of additional relevant information such as government, public, and private agencies and national and international organizations.

Assemble a task force to develop a catalog of published works and carefully screened unpublished works and to identify areas of unmet needs. The topics covered should include: functional assessment procedures, validated instructional materials and technologies, specialized equipment and apparatus, and specialized facilities.

Hold conferences for the demonstration of techniques as a supplement to published reports.

Determine if existing agencies can effectively implement an information system on education for the severely handicapped.

Develop formats for information categories that are relevant to the severely handicapped, especially: language, motor, and quantitative skills; prosthetic usage; caretaking; and premature-sequential development.

Develop an inventory of resources including people, disciplines, and published and unpublished materials.

Evaluate the effectiveness of different communications models as they compare by:

- Costs
- Efficiency in reducing the time between release of findings and their implementation
- Effectiveness in transmitting information and stimulating implementation

Evaluation

Measurement and evaluation were implied or mentioned specifically in most of the research needs identified during the conference. One group, however, singled out as the top-priority need the very special problems in evaluating programs for the severely handicapped. These problems center on three major concerns: materials and procedures for assessing the most severely handicapped, assessment tools that are sensitive to small changes during short time periods and related to specific components of intervention programs, and atypical evaluation

approaches that are appropriate for this population. Another group pointed out that measurement of progress is particularly important when studying the cost effectiveness of programs for the severely handicapped.

How can evaluation be used to determine how well intervention programs produce desired learning outcomes?

Establish evaluation parameters.

Determine the status of performance at fixed times during and after the program of intervention.

Determine the relationship between components of the intervention program and desired learning outcomes.

Develop strategies that can be used on a continuous basis for:

- Product evaluation (for both the student and the program)
- Process evaluation (for continuity of service)
- Predictive evaluation (for program planning)

How can evaluation be used to improve programs of intervention for the severely handicapped?

Design research to develop evaluation procedures, with particular emphasis on:

- Methods to replicate effective evaluation processes with a mechanism for maintaining quality control of the replications
- Improvement of the efficiency of the evaluation process

Develop effective, comprehensive evaluation systems that can be used for continuous evaluation and feedback of the results for program adjustment and improvement.

Design strategies for disseminating information on effective systems for evaluation.

How effective are educational programs in improving the life of the severely handicapped after formal schooling?

Develop and implement procedures for follow-up of children who have left the program to determine

how their educational experiences relate to later accomplishments.

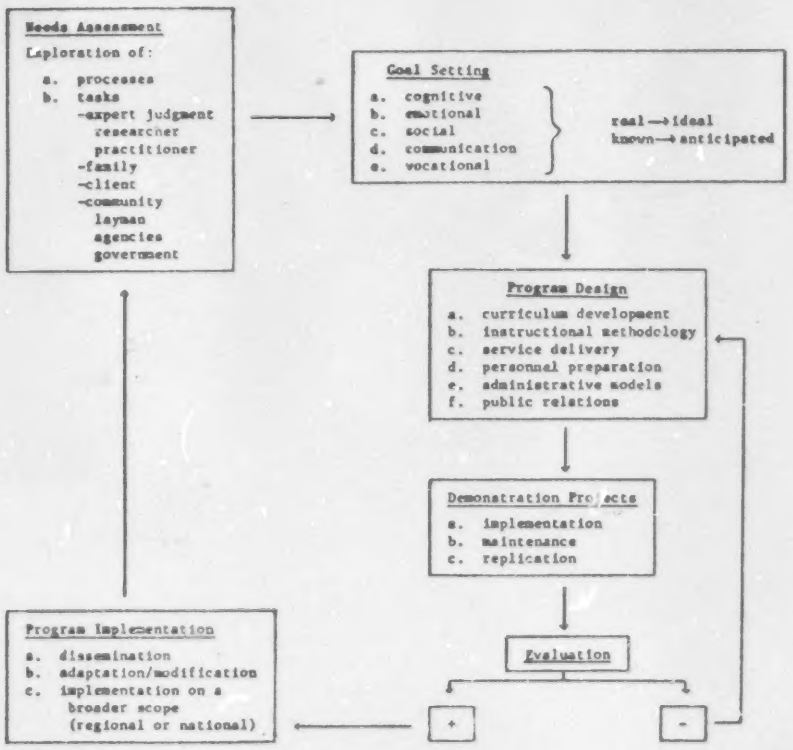
Determine the type and extent of learning needs for which future intervention must be planned.

Model for Research, Service Design, and Delivery

One group submitted a comprehensive research, service design, and delivery model (below) that illustrates the relationships among the critical program issues. It shows an ongoing system that starts with the assessment of need, goes into the setting of goals, to design of programs, to demonstration of projects, to evaluation of projects. Should the evaluation be negative, the process goes back to the program design to identify components that aren't working. If the evaluation is positive, the demonstration project is ready for implementation as a program. And then the reexamination of needs starts the cycle over again.

Figure 2

Comprehensive Research, Service Design, and Delivery Model



II. Additional Research Needs

Other needs for research that were considered by the participants to be critical but not top-priority are reported below.

Communication

Most of the communications-related issues reported during the conference are discussed under Information Exchange Systems on page 78. However, several additional issues were identified:

Is the community's need to know adequately served by the existing communications system?

Investigate ways to provide information to and input from the local community.

Evaluate the effectiveness of information programs as measured by:

- Increased political support and resource allocation
- Reduction of stigmas and increase in opportunities for the severely handicapped

Do those who have administrative and legislative responsibilities affecting the severely handicapped have the information they need in order to make reasoned decisions?

Survey how legislators and school board members presently collect and use information.

Determine what information they need.

Design programs for orientation, training, and information dissemination.

What special channels of communication are needed for medical personnel who must better understand the nature and needs of the severely handicapped?

Explore the use of seminars and workshops and the dissemination of information through professional journals.

How should parents be informed and what should they know about their severely handicapped child?

Develop strategies for informing and counseling parents that:

- Involve physicians, the clergy, teachers, and researchers
- Give particular emphasis to parents of young children
- Include information on expectations of level of achievement and limitations of the handicapped child

Evaluate the effectiveness of these communication strategies.

Is it feasible to use the services of a professional information disseminator to keep abreast of recent developments and facilitate their application by practitioners?

Is it possible to provide a common language for educational objectives for more effective communication among agencies?

Explore the feasibility of a computer-based system to provide classroom teachers with information on behavioral objectives and the strategies, resources, and skills needed to reach those objectives.

What special documents are needed by those who work with the severely handicapped?

Provide for an annual review with articles on important research efforts, their relative merits, and their application in the field. The articles should be written by leading authorities and should be nontechnical.

Develop a dictionary and resource handbook on handicapping conditions to provide information to educators, parents, and medical personnel on: etiology, symptoms and characteristics, range of progress, educational-living techniques, and resources available for various types of handicaps.

Commission a definitive state-of-the-art paper on research and evaluation in education for the severely handicapped. The paper should include appropriate input from other disciplines such as education, psychology, and statistics.

Management/Administration Systems

Many of the research needs and topics discussed earlier in this report include management and administrative components. The conference participants

did, however, identify certain critical areas of the management process itself which should be researched.

What competencies are needed by administrative personnel?

Conduct a task analysis of administrative positions and develop performance standards and competency statements for each position.

Assess skills needed for effective communication to various audiences.

Develop leadership qualities through preservice and continuing education experiences.

Identify the competencies required for planning and budgeting, interpersonal relations, and legal considerations.

What training in basic and effective management skills can be made available to personnel serving the severely handicapped?

Survey existing training opportunities.

Assess the need for management skills.

Develop and evaluate training programs.

How can cooperation be fostered among the different groups that provide assistance to the severely handicapped?

Analyze existing management models.

Develop management models that include:

- Consideration of allied services which are controlled and funded by different sources such as assessing staff, public school teachers, special education cooperative therapists, private practice clinicians, parents, and medical personnel
- Provision for coordination, feedback, and follow-up

Demonstrate effective models.

How can assessment and follow-up information be used to better advantage in program development?

Identify factors which promote--or impede--effective use of process evaluation for continuous assessment and the improvement of program goals, intervention strategies, data collection, and program evaluation.

Develop program management systems which incorporate the use of process evaluation in program design and implementation.

- Include identification of when and what decisions must be made and a process for decision making that facilitates program adjustment
- Investigate the use of conflict-resolution techniques such as the Delbecq nominal group method
- Study what effect participating in the decision-making process has on personnel satisfaction

How can the effectiveness of management systems be evaluated?

Develop strategies to evaluate the management of programs for the severely handicapped. Include as criteria:

- Changes in student performance
- Cost effectiveness
- Responsiveness to internal and external feedback

What are the indices of normalization?

Identify an exhaustive set of domains of human experience.

Determine levels of development in each, ranging from completely normal to completely abnormal.

Determine the appropriateness and/or value of programs for individual severely handicapped people.

Explore ways to implement normalization.

Nonverbal Communications Systems

What assessment procedures can be used with those who lack both an effective communication system and fine manipulative abilities?

Identify a hierarchy of prelanguage-level stages.

Evaluate available materials and strategies.

Determine what elements should be included in the assessment.

Develop new procedures to communicate with and assess this population.

Determine qualifications needed by personnel who conduct the assessment.

Personnel

What development of personnel resources is needed?

Determine the population of severely handicapped to be served and the population of personnel who serve the handicapped.

Identify the needs for specific kinds of personnel. Indicate curriculum, academic and experiential background of staff, and numbers of staff needed.

How do personnel training programs relate to school settings?

Consider how various patterns of personnel utilization indicate the need for differential training.

Study the cost effectiveness of training personnel for various staffing options.

Use pupil achievement as the criterion for evaluating different training models.

What teaching methods can be used to prepare teachers to deal with interpersonal relationships?

Determine the psychological mechanisms involved in interactions among parents, teachers, and children.

Identify training that is effective in preparing the teacher. Measure effectiveness in terms of the handicapped child's progress and the teacher's increased competence to serve the child.

What are appropriate roles for personnel who serve the severely handicapped adult?

Study characteristics of personnel presently serving handicapped adults.

Determine which characteristics are desirable.

Develop training models for the development of these personnel.

Are longitudinal educational services needed for personnel?

Determine factors related to providing learning opportunities including:

- Diagnosis of the need for instruction
- Curriculum content and sequence
- Instructional methods and materials
- Settings

Develop instructional models.

Conduct longitudinal studies to evaluate the effectiveness of the materials and models in terms of personnel development and employability.

What are the best ways of training personnel in multi-agency settings?

Develop a variety of approaches to specialized training for teachers, parents, paraprofessionals, administrators, foster parents, managers in group homes, and recreational and leisure-time personnel.

The Adult Severely Handicapped

Are existing methodologies effective for the education and training of the adult severely handicapped?

Determine the educational goals and learning settings that are most appropriate for this population.

Determine the significant physical, social, and intellectual characteristics that are unique to this group.

Analyze the applicability and efficacy of existing teaching technologies for handicapped adults in various learning situations.

Develop new technologies as needed.

Conduct long-term research and demonstration with service models that are successful in producing desired vocational, social, and personal outcomes.

What organizational structures are needed to provide continuity and coordination of quality services for the adult severely handicapped?

Conduct comparative studies of various organizational arrangements such as public and voluntary agencies at local and state levels.

Evaluate effectiveness as related to such criteria as client outcomes and costs.

Attitudes

How can positive attitudes toward the severely handicapped be fostered?

Determine the methods, instruments, and strategies that are needed to evaluate the affective dimensions of interpersonal relationships between the severely handicapped and others.

Relate skills to affective variables observed in the home, school, and work settings.

Determine cultural differences.

Identify and implement strategies for developing positive attitudes.

Assess the effectiveness of the strategies used in producing more desirable attitudes and changes in behavior.

Educational Goals

What are the life requirements of the severely handicapped?

Analyze requirements in a variety of environmental settings through observation and interviews with the handicapped and those responsible for their care and training.

What behavioral goals are desirable and realistic?

Determine separately for each of the key agents in the severely handicapped person's life (parents, practitioners, legislators, administrators, and the handicapped himself):

- Current goals
- Ultimate goals perceived as probable, possible, and preferred

- Effect of intervention on expectations
- Process by which goals are established and reevaluated

Explore the use of the Delphi technique in setting goals.

Study the impact of intervention strategies on modification of expectancies:

- Determine how the parents can be helped to develop goals for their severely handicapped children
- Determine how decision makers can best determine goals for the severely handicapped

How and to what extent does the severely handicapped child compensate for his disabilities?

Determine how these compensation mechanisms relate to achievement in specific educational programs.

Summary

At the Conference on Research Needs Related to Education of the Severely Handicapped, participants spoke repeatedly of the need for:

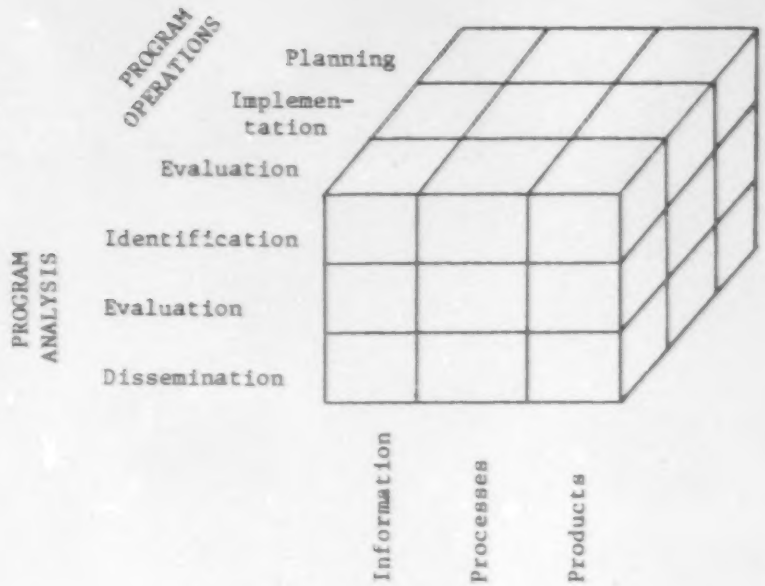
- An exchange of information between researchers and practitioners--both through direct, individual contact and through a large-scale, centralized center for information collection and dissemination
- A consortium--or task force--approach to building comprehensive models for services for the severely handicapped
- Systems for continuous surveillance for the prevention, early identification, and amelioration of handicapping conditions

The participants felt very strongly that research has been so fragmented in the past that it has not had a significant impact on the education of the severely handicapped. This conference should result in the setting of priorities for research and a major commitment to a few of the most critical needs first. Other needs can be addressed later--again with commitments to large-scale, comprehensive approaches to solving critical problems.

A study of the participants' reports suggests the model for research related to the conference recommendations shown in Figure 3.

Figure 3

Model for Research Related to
Education for the Severely Handicapped



Assuming that any one of the priority needs can be considered a program, this model can then be used to formulate research projects. Consider, for example, the following research need: to develop effective means to educate and counsel school-age children on parenthood. Here are some related topics for research that could be derived from the model:

- Identify information on planning programs to teach the severely handicapped adolescent about parenthood
- Evaluate information on planning programs to teach severely handicapped adolescents about parenthood
- Devise strategies for the dissemination of products used in evaluating programs designed to teach severely handicapped adolescents about parenthood

Reports submitted by individuals as well as by groups at the conference provide a great deal of detail that will be an invaluable resource to the Bureau of Education for the Handicapped. But perhaps one of the greatest benefits of the conference was the opportunity it provided for colleagues to work intensively together toward the common goal of better service to the severely handicapped.

APPENDIX A:
Steering Committee Members

STEERING COMMITTEE MEMBERS

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